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## Dementia, Autonomy, and Supported Healthcare Decision Making

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## DEMENTIA, AUTONOMY, AND SUPPORTED HEALTHCARE DECISIONMAKING

MEGAN S. WRIGHT\*

### ABSTRACT

*Healthcare providers often rely on surrogates to decide on behalf of their patients with dementia who are deemed incapable of exercising autonomy. There is a longstanding debate about the appropriate standard of surrogate healthcare decisionmaking for these patients. Many influential scholars argue that the precedent autonomy of the person with dementia should be respected, and healthcare decision-making laws generally reflect this principle. These laws direct surrogate decisionmakers to follow instructions in living wills or to decide on the basis of the wishes and values of the person before the onset of dementia. But other prominent scholars have questioned whether surrogates should instead use the best interests standard, which accounts for the current interests of the person with dementia.*

*This debate about decision-making standards ignores an arguably more important issue: who should be deciding? Empirical research demonstrates that persons with mild dementia retain the ability to make or participate in decisions despite their acquired cognitive impairments, and that they prefer to be actively involved in healthcare decisionmaking. However, persons with dementia*

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*are routinely marginalized in the decision-making process, which leads to a decline in their psychological wellbeing.*

*Based on studies of their decision-making abilities, preferences, and experiences, this Article will argue that persons with dementia should not be prevented from making their own healthcare decisions. Stated differently, persons with dementia should have the legal right to make their own healthcare decisions at the time when the decisions need to be made. Ensuring this right will require looking beyond surrogate-based healthcare decision-making law, which facilitates the exclusion of persons with dementia from decisionmaking.*

*Disability law in six U.S. jurisdictions provides an alternative decision-making model, known as supported decisionmaking, which empowers persons with cognitive impairments to make their own decisions and could be usefully applied to dementia. In supported decisionmaking, an adult with a disability (the “principal”) voluntarily chooses people to assist them in decisionmaking (a “supporter”) and formalizes this arrangement in a written agreement. The supporter’s role is to help the principal gather relevant information, think through the decision, and convey the decision to other people. Supported decisionmaking preserves the legal decision-making authority of a person with a disability rather than transferring such authority to a surrogate. Because supported decisionmaking accords with the preferences and interests of persons with dementia, supported decision-making laws should be widely adopted.*

*This novel application of supported decisionmaking to dementia also provides insight into the nature of autonomy in the larger context of late-life healthcare decisionmaking. My past research has demonstrated that autonomous decisionmaking in this context is relational, which is consistent with supported decisionmaking. This Article will further build upon this conceptualization and advance a new understanding of autonomy in healthcare decisionmaking as more closely approximating relational agency. With this revised understanding of autonomy and the adoption of supported decisionmaking, persons with dementia can remain autonomous for longer in the progression of their disease.*

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## INTRODUCTION

There is a longstanding debate in the law and philosophy literature, and in medical practice and clinical scholarship, about dementia and decisionmaking. Dementia is a degenerative disorder that, over time, results in significant cognitive decline and the need for assistance with activities of daily living. Assistance is also sometimes needed when making medical decisions, and surrogate (i.e., substitute) decisionmakers are often relied upon. The use of surrogate decisionmaking for persons with dementia leads to questions about how surrogates should make decisions. Many influential scholars argue the precedent autonomy of the person with dementia should be respected,<sup>1</sup> and healthcare decision-making law generally reflects this principle by instructing surrogates to follow instructions in living wills or to decide on

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1. See, e.g., RONALD DWORKIN, LIFE’S DOMINION 222–29 (1993).

the basis of the prior wishes and values of the person with dementia.<sup>2</sup> But other prominent scholars have questioned whether the best interests standard, which accounts for current interests and preferences even if they conflict with past wishes, should instead be the default for this population.<sup>3</sup>

An example that illustrates the tension over decision-making standards concerns the “happy demented patient” whose current experiential interests seem to conflict with their interests prior to the onset of dementia.<sup>4</sup> Many versions of this example circulate in philosophical scholarship, but the main features are the following: An individual has a legally binding advance directive that instructs that life-sustaining treatment be withheld should they develop dementia. They then acquire dementia, progressing to the point in their illness where they have moderate cognitive decline, but seem to be content, experience pleasure, and are capable of expressing a fear of dying. Then they encounter further health problems, and healthcare providers and surrogate decisionmakers consult their advance directive to decide whether a low-burden life-sustaining intervention, such as an antibiotic, should be administered.<sup>5</sup> Healthcare decision-making law, premised on respect for autonomy, directs surrogate decisionmakers to follow the advance directive and decline the life-saving intervention. Allowing the person with dementia to die in order to respect an abstract principle may cause moral distress to surrogates and healthcare professionals, however, because doing so does not necessarily seem to be in the current best interest of the patient, which is to continue living a content, pleasurable life.<sup>6</sup>

This Article will step back from the ongoing and perhaps irresolvable debates about which surrogate decision-making standards are ethically superior to engage a question that is logically prior: *Should persons with dementia*

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2. See, e.g., UNIF. HEALTH CARE DECISIONS ACT prefatory note (NAT’L CONFERENCE OF COMM’RS ON UNIF. STATE LAWS 1994) [hereinafter UHCDA].

3. E.g., Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373 (1986) [hereinafter Dresser, *Life, Death, and Incompetent Patients*]; Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609 (1994) [hereinafter Dresser, *Missing Persons*]; Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823 (2003) [hereinafter Dresser, *Precommitment*]. In the absence of an advance directive, the best interests standard is used in some states when a patient lacks capacity. See, e.g., IND. CODE ANN. § 16-36-1-5(d) (LexisNexis 2016). This standard is a last resort for states that privilege substituted judgments. UHCDA, *supra* note 2, § 2(e).

4. See TIA POWELL, *DEMENTIA REIMAGINED: BUILDING A LIFE OF JOY AND DIGNITY FROM BEGINNING TO END* 257–58 (2019); Deena S. Davis, *Advance Directives and Alzheimer’s Disease*, 46 J. L. MED. & ETHICS 744, 746–47 (2018); Dresser, *Missing Persons*, *supra* note 3, at 624–25; Jennifer Hawkins, *Well-Being, Time, and Dementia*, 124 ETHICS 507–08 (2014); see also Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value*, 28 PHILOSOPHY & PUB. AFF. 105, 107 (1999) (describing a sad demented patient).

5. Hawkins, *supra* note 4, at 508; see also Paul T. Menzel & Bonnie Steinbock, *Advance Directives, Dementia, and Physician-Assisted Death*, 41 J. L. MED. & ETHICS 484 (2013).

6. Davis, *supra* note 4, at 746–47.

*be legally entitled to make their own healthcare decisions at the time a decision needs to be made?* Grounded in the lived experiences and decision-making preferences of persons with dementia, this Article will answer in the affirmative.

Indeed, what is often missing in the extant legal and bioethics scholarship on dementia and decisionmaking is the perspective of persons with dementia.<sup>7</sup> Empirical literature demonstrates that persons with dementia prefer to be actively involved in decisions that affect their lives, but often are marginalized, ignored, or excluded from the decision-making process.<sup>8</sup> This is true even in the early stages of dementia, when significant cognitive abilities remain and persons are capable of participating.<sup>9</sup> Being prevented from making or participating in decisions has a negative impact on the wellbeing of persons with dementia who report feeling that they are not recognized as people, but instead are treated as objects.<sup>10</sup>

This Article is the first to engage in depth with whether the practice of permitting surrogates to make healthcare decisions for persons with dementia, which is facilitated by healthcare decision-making law, should be changed. To date, reference to persons with dementia making their own healthcare decisions in legal and bioethical scholarship tends to be brief and conclusory in nature.<sup>11</sup> Advice for lawyers who have clients with dementia similarly lacks acknowledgement that persons with dementia may be able to make their own healthcare decisions at the time they need to be made.<sup>12</sup> The focus is instead on how to ensure that others make good decisions on behalf of the person with dementia.

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7. The goal of many legal academics and bioethicists writing in this area is to identify legal tools by which to avoid living with dementia, a condition they consider intolerably degrading. Clinicians and social scientists are more likely to foreground the perspectives of persons with dementia.

8. See, e.g., Lyndsey M. Miller et al., *Shared Decision-Making in Dementia: A Review of Patient and Family Carer Involvement*, 15 DEMENTIA 1141, 1142–43 (2016).

9. Persons with dementia are, therefore, excluded even when they are legally entitled to make their own decisions because they retain decisional capacity. See *infra* Sections I.B, I.C, and IV.A.1.

10. See, e.g., Alison Phinney, *Living with the Symptoms of Alzheimer's Disease*, in THE PERSON WITH ALZHEIMER'S DISEASE: PATHWAYS TO UNDERSTANDING THE EXPERIENCE 49 (Phyllis Braudy Harris ed., 2002); Rosalie F. Young, *Medical Experiences and Concerns of People with Alzheimer's Disease*, in THE PERSON WITH ALZHEIMER'S DISEASE, *supra*, at 29, 38–41, 44.

11. See, e.g., Chris Fox et al., *Clinical Management of Dementia: An Overview (2)*, in THE LAW AND ETHICS OF DEMENTIA 65, 81 (Charles Foster et al. eds., 2014) (“A whole chapter or more could be devoted to the discussion on involving patients in decision making. We merely note . . . that ‘treatment and care should take into account patients’ needs and preferences and patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.”); see also Rebekah Diller, *Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making*, 43 FORDHAM URB. L.J. 495 (2016) (focusing on older adults, but occasionally discussing Alzheimer's Dementia).

12. KERRY PECK & RICK L. LAW, ALZHEIMER'S AND THE LAW: COUNSELING CLIENTS WITH DEMENTIA AND THEIR FAMILIES 74 (2013).

This oversight is surprising given that international and domestic disability law provides an alternative decision-making model—known as supported decisionmaking—that empowers persons with cognitive disabilities to make their own decisions.<sup>13</sup> Supported decisionmaking preserves the legal decision-making authority of a person with a disability rather than transferring such authority to a surrogate. Under this model, an adult with a disability (the “principal”) voluntarily chooses people to assist them in decisionmaking (a “supporter”), and may formalize this arrangement in a written agreement.<sup>14</sup> The supporter’s role is to help the principal gather relevant information, think through the decision, and convey the decision to other people.<sup>15</sup> In contrast to the emphasis on autonomy in healthcare decision-making law, supported decisionmaking emphasizes agency, self-determination, respect for personhood, bodily integrity, and relationships with others. Supported decisionmaking originated for persons with developmental and intellectual disabilities and is currently being explored for persons with mental illnesses.<sup>16</sup>

Given that dementia is a disability,<sup>17</sup> applying decision-making models found in disability law rather than healthcare decision-making law may be beneficial in identifying the best decision-making practices for this population. The emphasis on decisional capacity in healthcare decision-making law, coupled with presumptions of incompetence that begin upon diagnosis of dementia,<sup>18</sup> allow others to disregard the agency of the person with dementia and take over decisionmaking. In order to improve their wellbeing, persons with dementia who prefer to make or participate in decisions should not be prevented from doing so, especially in the context of healthcare decisionmaking that affects what happens to their body and whether they live or die.<sup>19</sup> Under a legally enforceable supported decision-making agreement, persons with dementia would be assured of a legal entitlement to make their

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13. Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1113 (2013).

14. See, e.g., TEX. EST. CODE ANN. § 1357.051(1)–(4) (West 2018).

15. *Id.*

16. See, e.g., PIERS GOODING, A NEW ERA FOR MENTAL HEALTH LAW AND POLICY: SUPPORTED DECISION-MAKING AND THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2017); Dilip V. Jeste et al., *Supported Decision Making in Serious Mental Illness*, 81 PSYCHIATRY: INTERPERSONAL & BIOLOGICAL PROCESSES 28, 28–29 (2018).

17. The Americans with Disabilities Act of 1990 (“ADA”) defines disability as “(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment (as described in paragraph (3)).” 42 U.S.C. § 12102(1) (2012).

18. RENEE BEARD, LIVING WITH ALZHEIMER’S: MANAGING MEMORY LOSS, IDENTITY, AND ILLNESS 63, 82–83, 109–110 (2016).

19. Healthcare decisions are especially important because the consequences of these decisions affect all other decisions. Decisions such as where to live (e.g., whether to move to an assisted living facility) also matter to persons with dementia. But unlike healthcare decisions that primarily affect the person with dementia (whose body bears the costs and benefits of the decision), other types of decisions may affect third parties whose interests are appropriate to consider.

own decisions should this be their preference. Supported decisionmaking is thus consistent with the interests of persons with dementia, who desire to be viewed as *people* capable of exercising agency.

Therefore, if institutionalized as a legal alternative to surrogate decisionmaking, supported decisionmaking would likely increase wellbeing for persons with dementia. Further, supported decisionmaking would increase the likelihood that persons with dementia could remain autonomous for longer in the progression of their disease, if autonomy is appropriately understood.

Indeed, this Article is the second in a series that relies upon the lived experiences of people facing late- and end-of-life decisionmaking to argue that traditional conceptualizations of autonomy in health law require revision. The first article in this series demonstrated that, in contrast to the dominant understanding of autonomy as individualistic, most people understand autonomy to be relational; that is, they make end-of-life decisions with others and perhaps even on the basis of others' interests, and still view themselves as autonomous decisionmakers.<sup>20</sup> Additionally, the earlier article argued that healthcare decision-making laws meant to effectuate autonomy may actually hinder it because such laws are premised on a "derelationalized" understanding of autonomy.<sup>21</sup>

This Article will use the case of dementia to build upon my previous arguments about autonomy in healthcare decisionmaking in several ways. First, I will argue that dementia is not necessarily incompatible with autonomy, and that persons with mild to moderate dementia are capable of autonomous decisionmaking, if autonomy is properly conceptualized as relational. Indeed, if persons with dementia can make healthcare decisions in consultation and collaboration with supporters they have selected, this would be consistent with how persons without dementia prefer to make important decisions. Supported decisionmaking formalizes how many people prefer to decide, regardless of whether they have a disability that impairs cognition. Using supported rather than surrogate decisionmaking thus promotes *relational autonomy*.

Second, this Article will demonstrate that the existing literature on the relationship between dementia and autonomy obscures an important reality: Persons with dementia retain significant cognitive capabilities despite their impairments, and persons without dementia often do not act autonomously.<sup>22</sup> Indeed, autonomous decisionmaking as defined in much of the philosophical

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20. Megan S. Wright, *End of Life and Autonomy: The Case for Relational Nudges in End-of-Life Decision-Making Law and Policy*, 77 MD. L. REV. 1062, 1093 (2018).

21. *Id.* at 1100.

22. *Id.* at 1096–1101.



literature<sup>23</sup> may be impossible even for persons without dementia. This is because cognitive biases distort rationality and prevent people from making decisions that further their interests, and because structural factors, such as poverty, limit available choices.<sup>24</sup> It is thus more accurate to describe most decisionmaking as agentic. So described, agentic decisions are also possible for persons with dementia who, in the early to middle stages, remain able to communicate preferences and make choices,<sup>25</sup> and with support could make decisions that align with their preferences, interests, and values. If equality is valued, then instead of privileging an idealized version of autonomy in law and medicine, which even persons without cognitive impairments cannot meet and which results in disparate treatment of persons with dementia, the decisions of all who can decide *agentially* should be respected.

The Article will proceed in four parts. In Part I, a brief orientation to dementia, will provide basic familiarity with the features of this disability. This Part will also summarize surrogate healthcare decision-making law, which is often applied to persons with dementia. This Part will conclude by describing the decision-making preferences of persons with dementia and will demonstrate that existing law and clinical practice do not accord with these preferences. Part II will argue that law and practice should better align with the preferences of persons with dementia, in order to respect their agency and increase their wellbeing. Part III will describe supported decisionmaking, which is more consistent with the interests of persons with dementia than surrogate decisionmaking, and argue that this model should be widely adopted. Part IV will evaluate the scope conditions of and address possible objections to persons with dementia using supported decisionmaking. This Article will conclude with a discussion of how autonomy should be reconceptualized in healthcare decision-making law, advancing the concept of *relational agency*.

## I. LIVING AND MAKING HEALTHCARE DECISIONS WITH DEMENTIA

Millions of people are affected by dementia, including the estimated four to five million Americans who have some type of dementia and their family members.<sup>26</sup> The question of how to provide appropriate care for persons with dementia is a pressing health policy question as the numbers of

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23. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 104 (7th ed. 2013) (defining “autonomous action in terms of normal choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action”).

24. Wright, *supra* note 20, at 1096–1101; *see also* Susan Sherwin, *Relational Autonomy and Global Threats*, in *BEING RELATIONAL: REFLECTIONS ON RELATIONAL THEORY AND HEALTH LAW* 13 (Jocelyn Downie & Jennifer L. Llewellyn eds. 2012).

25. *See, e.g.*, Miller et al., *supra* note 8, at 1142–43.

26. Gina Kolata, *U.S. Dementia Rates Are Dropping Even as Population Ages*, N.Y. TIMES (Nov. 21, 2016), [https://www.nytimes.com/2016/11/21/health/dementia-rates-united-states.html?\\_r=0](https://www.nytimes.com/2016/11/21/health/dementia-rates-united-states.html?_r=0).

persons with dementia increase,<sup>27</sup> and there is still no cure or prevention for dementia.<sup>28</sup>

In order to provide an orientation to the issue of dementia and healthcare decisionmaking, this Part first defines and describes dementia. It then outlines the law governing healthcare decisionmaking for persons with impaired decisional capacity, which includes persons with dementia. Finally, this Part concludes by summarizing the empirical literature on the healthcare decision-making abilities, preferences, and experiences of persons with dementia.

### A. Definition and Epidemiology of Dementia

Dementia is an umbrella term that refers to a variety of neuropsychiatric conditions that impair cognitive functions.<sup>29</sup> Put simply, “[d]ementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities.”<sup>30</sup> Alzheimer’s dementia (“AD”) is the most common dementia, accounting for over sixty percent of all cases.<sup>31</sup> Other common types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia.<sup>32</sup> Dementia also can be caused by Parkinson’s disease, Huntington’s disease, multiple sclerosis, traumatic brain injury, and other conditions.<sup>33</sup>

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27. WORLD HEALTH ORG., DEMENTIA: A PUBLIC HEALTH PRIORITY (2012), [https://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](https://www.who.int/mental_health/publications/dementia_report_2012/en/).

28. *Id.* at 8.

29. *What is Dementia?*, NAT’L INSTITUTE ON AGING, <https://www.nia.nih.gov/health/what-dementia>; see also Elissa L. Ash, *What is Dementia?*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 3, 3–5.

30. WORLD HEALTH ORG., *supra* note 27, at 2, 7. There are many different definitions of dementia in the clinical literature, but for a comprehensive definition that covers dementia due to all causes see Guy M. McKhann et al., *The Diagnosis of Dementia Due to Alzheimer’s Disease: Recommendations from the National Institute on Aging-Alzheimer’s Association Workgroups on Diagnostic Guidelines for Alzheimer’s Disease*, 7 *ALZHEIMER’S & DEMENTIA* 263 (2011); see also Ash, *supra* note 29, at 4–5.

31. WORLD HEALTH ORG., *supra* note 27, at 7; see also MICHAEL CASTLEMAN ET AL., *THERE’S STILL A PERSON IN THERE: THE COMPLETE GUIDE TO TREATING AND COPING WITH ALZHEIMER’S* 30–31 (1999) (describing warning signs of Alzheimer’s).

32. WORLD HEALTH ORG., *supra* note 27, at 19. “Early in the disease course these different types of dementia can impair specific cognitive processes, such as memory, language, behavior, or executive functions, but all types of dementia can impair decision making.” R. Ryan Darby & Bradford C. Dickerson, *Dementia, Decision-Making, and Capacity*, 25 *HARV. REV. PSYCHIATRY* 270, 270 (2017).

33. CASTLEMAN ET AL., *supra* note 31, at 125–44; Ash, *supra* note 29, at 9.

Just as there are different types of dementia, there are different degrees of dementia as well. Dementia can be classified as mild, moderate, or severe;<sup>34</sup> most persons with dementia have mild dementia, and less than a quarter of persons with dementia have severe dementia.<sup>35</sup> Someone with mild dementia may have problems doing “complex tasks”<sup>36</sup> they used to do with ease such as “bill paying, cooking, housecleaning, and traveling.”<sup>37</sup> Or a person may lose the ability to write, but can still think and speak in a manner that conveys sophisticated thoughts.<sup>38</sup> A person with moderate dementia may require a more significant amount of assistance with daily activities such as maintaining hygiene and getting dressed, and, while retaining verbal abilities and the ability to engage in activities such as eating and painting, may evidence severe memory deficits and be unable to read.<sup>39</sup> A person in the later stages of dementia may be incontinent, nonverbal, and unable to eat without assistance or artificial nutrition and hydration.<sup>40</sup> Persons with late stage dementia may also have psychiatric symptoms, which “may include paranoia, delusions, hallucinations, agitation, restlessness and socially inappropriate or aggressive behavior.”<sup>41</sup> The experience of dementia also depends on an individual’s prior psychological characteristics<sup>42</sup> and their current social environment.<sup>43</sup>

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34. McKhann et al., *supra* note 30, at 265; *see also* CASTLEMAN ET AL., *supra* note 31, at 38–40 (describing stages of dementia); Ash, *supra* note 29, at 4; WORLD HEALTH ORG., *supra* note 27, at 7 (describing common symptoms of dementia by early, middle, and late stages).

35. POWELL, *supra* note 4, at 213 (“Mild to moderate dementia lasts for years . . .”); Menzel & Steinbock, *supra* note 5, at 486 (citing statistics).

36. *See* ANNE KENNY, MAKING TOUGH DECISIONS ABOUT END-OF-LIFE CARE IN DEMENTIA 16–17 (2018); *see also* CASTLEMAN ET AL., *supra* note 31, at 39.

37. Menzel & Steinbock, *supra* note 5, at 486 (citing the Functional Assessment Staging Test (“FAST”)).

38. *See id.* at 492 (describing a case of early stage AD).

39. *See, e.g., id.* at 486 (describing moderate dementia); *see also* KENNY, *supra* note 36 (describing symptoms at Stage 5 to 6C of the FAST scale); Paul T. Menzel & Colette Chandler-Cramer, *Advance Directives, Dementia, and Withholding Food and Water by Mouth*, HASTINGS CTR. REP., May–June 2014, at 23, 27 (describing a woman with moderate dementia).

40. *See, e.g.,* KENNY, *supra* note 36 (describing symptoms at Stages 6d to 7f of the FAST scale); Menzel & Steinbock, *supra* note 5, at 486; Menzel & Chandler-Cramer, *supra* note 39, at 23 (describing a person with late-stage dementia).

41. Patrick P. Coll, *Legal and Ethical Issues at the End-of-Life: Dementia*, 23 QUINNIPIAC PROB. L.J. 378, 383 (2010).

42. WORLD HEALTH ORG., *supra* note 27, at 7.

43. TOM KITWOOD, DEMENTIA RECONSIDERED, REVISITED: THE PERSON STILL COMES FIRST 84–85 (Dawn Brooker ed., 2d. ed. 2019) (arguing that all dementia experiences are unique); *see also* POWELL, *supra* note 4, at 212–14 (arguing for altering the environment to try to make life with dementia as pleasant as possible).

Separate from but related to dementia is the diagnostic category of mild cognitive impairment (“MCI”). MCI may be a precursor to AD, but the individual does not yet meet the clinical standard for a diagnosis of AD.<sup>44</sup> A diagnosis of MCI requires: “concern about a change in cognition, in comparison with the person’s previous level”; “lower performance in one or more cognitive domains that is greater than would be expected for the patient’s age and educational background”; “mild problems performing complex functional tasks which they used to perform previously”; and “cognitive changes . . . sufficiently mild [such] that there is no evidence of a significant impairment in social or occupational functioning.”<sup>45</sup> Not everyone who has MCI will develop dementia.<sup>46</sup>

The onset of dementia typically occurs in later life,<sup>47</sup> and as the number of older persons in a society increases, there will be more people living with dementia.<sup>48</sup> In the United States, the estimated rate of dementia from all causes for people over sixty is 6.77%,<sup>49</sup> and AD is the sixth leading cause of death.<sup>50</sup> While the rate of dementia is decreasing, the number of people living with dementia is rapidly increasing,<sup>51</sup> as are the costs associated with providing dementia-related care.<sup>52</sup> Dementia patients currently make up about fifty percent of all nursing home residents, about forty percent of residential care community residents, and about thirty percent of adult day services center participants.<sup>53</sup> In response to this public health problem, recent legislation known as the BOLD Act (Building Our Largest Dementia Infrastructure for

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44. Marilyn S. Albert et al., *The Diagnosis of Mild Cognitive Impairment Due to Alzheimer’s Disease: Recommendations from the National Institute on Aging-Alzheimer’s Association Workgroups on Diagnostic Standards for Alzheimer’s Disease*, 7 ALZHEIMER’S & DEMENTIA 270 (2011); Ash, *supra* note 29, at 5–6; Jennifer N. Vega & Paul A. Newhouse, *Mild Cognitive Impairment: Diagnosis, Longitudinal Course, and Emerging Treatments*, 16 CURRENT PSYCHIATRY REP. 490 (2014).

45. Albert et al., *supra* note 44, at 271–72.

46. Ash, *supra* note 29, at 6.

47. WORLD HEALTH ORG., *supra* note 27, at 12, 15. Fewer than ten percent of people with dementia are under age sixty-five. *Id.* at 8.

48. Israel Doron, *The Demographics of Dementia*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 15, 18.

49. WORLD HEALTH ORG., *supra* note 27, at 14.

50. *Alzheimer’s Disease Fact Sheet*, NAT’L INST. ON AGING, <https://www.nia.nih.gov/health/alzheimers-disease-fact-sheet> (last reviewed May 22, 2019); see also Robert H. Blank, *Alzheimer’s Disease—Perspective from Political Science: Public Policy Issues*, 46 J. L. MED. & ETHICS 724, 727 (2018) (noting that this statistic is likely an underestimate).

51. WORLD HEALTH ORG., *supra* note 27, at vi, 2, 8, 90.

52. Blank, *supra* note 50, at 727–28; WORLD HEALTH ORG., at 2, 8, 25–28, 90.

53. *Alzheimer Disease*, NAT’L CTR. HEALTH STAT., <https://www.cdc.gov/nchs/fastats/alzheimers.htm> (last reviewed Mar. 11, 2016).

Alzheimer's Act)<sup>54</sup> was recently signed into federal law and is meant to spur research into prevention and detection of dementia.<sup>55</sup>

Given the interactions between type and stage of dementia, in combination with the unique individual and social characteristics of persons with dementia (e.g., level of family support and education), persons with dementia will experience their disability differently.<sup>56</sup> The universal parts of the experience of dementia are limited to the onset of a cognitive impairment, and the new relevance of laws that permit others to make decisions on behalf of persons with dementia.<sup>57</sup>

### *B. Law of Healthcare Decisionmaking for Persons with Impaired Decisional Capacity*

Respect for autonomy is the foundation of health law and ethics. Because of this principle, adults have the legal right to make their own healthcare decisions, provided they have not been adjudicated incompetent or been found by a clinician to lack decision-making capacity. If a person is found to lack the capacity to consent to medical treatment, however, then the law provides a process for surrogate decisionmakers to decide on their behalf, using the patient's values, beliefs, and preferences to guide their decision in order to respect the prior autonomy of the presently incapacitated patient. Because dementia often affects decision-making abilities, physicians and judges rely on surrogate decisionmakers when a healthcare decision needs to be made for a person with dementia. This Section describes surrogate healthcare decision-making law in the United States.

#### *1. Surrogate Decisionmaking and Dementia*

To effectuate respect for patient autonomy that survives a loss of decision-making capacity, all states have healthcare decision-making laws designed to facilitate decisions made on the basis of the incapacitated person's prior wishes. For example, competent persons can use a power of attorney to designate an agent to make decisions for them in the event of future inca-

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54. Pub. L. No. 115-406, 132 Stat. 5362 (2018).

55. Howard Gleckman, *The Anti-Alzheimer's BOLD Act Isn't. But It Could Be A Step in The Right Direction*, FORBES (Jan. 9, 2019), <https://www.forbes.com/sites/howardgleckman/2019/01/09/the-anti-alzheimers-bold-act-isnt-but-it-could-be-a-step-in-the-right-direction/#33ddb35ba56d>.

56. KITWOOD, *supra* note 43, at 84–85.

57. Another universal experience is that of stigma. Nancy Berlinger & Mildred Z. Solomon, *Becoming Good Citizens of Aging Societies*, 48 HASTINGS CTR. REP., Sept.–Oct. 2018, at S2, S7 (“Dementia is the most feared, stigmatized, and costly age-associated condition.”); Tia Powell, *“Tho’ Much Is Taken, Much Abides”: A Good Life Within Dementia*, 48 HASTINGS CTR. REP., Sept.–Oct. 2018, at S71.

capacity. People can also write a living will that provides decision-making instructions for surrogate decisionmakers to follow should the individual be unable to make their own decisions.<sup>58</sup>

Physicians rather than judges typically find that a person lacks the capacity to make their own healthcare decisions,<sup>59</sup> a finding that then triggers reliance on advance directives and use of surrogates. When a patient's decision-making capacity is in question, as may be the case when a person has dementia or other conditions that impair cognition, a trained provider may conduct a formal capacity assessment.<sup>60</sup> This assessment "involves determining an individual's ability to understand and retain relevant information, appreciate the nature and consequences of the decision and express [their] decision."<sup>61</sup> A person may have capacity to make some types of decisions but not others, and capacity is "decision-specific," or varies by decision, and

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58. Michael Schindler & Yael Waksman, *Restriction of Liberty*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 351, 354–55.

59. Rebecca Dresser, *Autonomy and Its Limits in End-of-Life Law*, in *THE OXFORD HANDBOOK OF U.S. HEALTH LAW* 399, 402 (I. Glenn Cohen et al. eds., 2017) ("[I]t would be unrealistic and unwarranted to require judicial evaluations in every case.").

60. There is evidence that capacity assessments are not occurring, and incapacity is instead presumed when someone has dementia. Miller et al., *supra* note 8. This is deeply problematic because under current law, loss of decision-making authority should only occur when someone is found to not have capacity. Even when capacity assessments occur, they tend to be informal. Jennifer Moyer & Daniel C. Marson, *Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research*, 62 J. GERONTOLOGY P3 (2007).

61. Gary Sinoff & Natalia Blaja-Lisnic, *Advance Decisions and Proxy Decision-Making in the Elderly: A Medical Perspective*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 97, 98; see also Paul S. Appelbaum & Thomas Grisso, *Assessing Patients' Capacities to Consent to Treatment*, 319 NEW ENGLAND J. MED. 1635, 1635 (1988) (defining capacity as "communicating a choice, understanding relevant information, appreciating the current situation and its consequences, and manipulating information rationally").

There are many critiques of capacity assessments. For example, "[a] patient's communication difficulties, fear, ambivalence, or hostility to medical professionals can lead evaluators to mistakenly label the patient incompetent." Dresser, *supra* note 59, at 402. This may be especially true for persons with dementia who feel controlled by others and are upset and subsequently rebel. Deirdre Fetherstonehaugh et al., *Being Central to Decision Making Means I Am Still Here!: The Essence of Decision Making for People with Dementia*, 27 J. AGING STUDIES 143, 146–47 (2013). Additionally, capacity assessments may rely too heavily on verbal abilities and "miss the opportunity to provide cues and supports to maximize comprehension and minimize memory demands." Moyer & Marson, *supra* note 60, at P7. Furthermore, it is not at all clear that persons with typical decision-making abilities and no disabilities would be found to have capacity if formally evaluated. See also CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS* (1998) (demonstrating the failure of informed consent). Finally, there is only "limited agreement between evaluations by multiple clinicians, multiple measures, or between a clinician and a measure, especially for the standards of appreciation and reasoning." Moyer & Marson, *supra* note 60, at P7; see also Diller, *supra* note 11, at 529–30 (discussing unreliability of capacity assessments). This may occur because capacity assessments are not free from value judgments. A capacity determination "necessarily reflects a balancing of two important, sometimes competing objectives: to enhance the patient's well-being and to respect the person as a self-determining individual." PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL AND BEHAVIORAL RESEARCH, *MAKING HEALTH CARE DECISIONS* 57 (1982).

may also fluctuate over time.<sup>62</sup> Someone may be able to consent to a medical intervention, but may have difficulty making financial decisions, for example.<sup>63</sup> Indeed, “[a] patient with early dementia may understand the benefits and risks associated with surgery and decide for [themselves] whether [they are] willing to undergo the procedure,”<sup>64</sup> but may reside in an assisted living facility because they need assistance with many activities of daily living.

While there are critiques of advance directives,<sup>65</sup> many medical and legal professionals advise their patients or clients with dementia to complete an advance directive soon after they are diagnosed, while they still have decisional capacity.<sup>66</sup> Creating an advance directive communicates the person’s wishes regarding treatment, and the hope is that these wishes later will be followed.<sup>67</sup> Legal scholars writing about dementia also often advocate for creating advance directives anticipating a possible future onset of dementia, with detailed instructions about how to ensure that death can be hastened should one acquire dementia.<sup>68</sup> Most people do not engage in advance planning, however.<sup>69</sup>

For individuals without advance directives, state law provides a default system of surrogates who can make decisions on behalf of an incapacitated

62. Bob Woods & Rebeka Pratt, *Awareness in Dementia: Ethical and Legal Issues in Relation to People with Dementia*, 9 AGING & MENTAL HEALTH 423, 425 (2005); see also KENNY, *supra* note 36, at 80 (describing difficulty of determining capacity for patients with dementia); Bruce Jennings, *Alzheimer’s Disease: Quality of Life and the Goals of Care*, in THE ROUTLEDGE COMPANION TO BIOETHICS 437, 446 (John D. Arras et al. eds., 2015) (describing capacity as a matter of degree for persons with Alzheimer’s).

63. Fetherstonehaugh et al., *supra* note 61, at 144.

64. Coll, *supra* note 41, at 379.

65. See, e.g., POWELL, *supra* note 4, at 256–61 (describing problems with advance directives); Blank, *supra* note 50, at 737; Dresser, *Precommitment*, *supra* note 3, at 1829–37 (describing problems with precommitment); Sinoff & Blaja-Lisnic, *supra* note 61, at 98, 100 (describing problems with precommitment); Wright, *supra* note 20, at 1133 n.387 (noting that these forms are derelationalized).

66. NANCY L. MACE & PETER V. RABINS, *THE 36-HOUR DAY: A FAMILY GUIDE TO CARING FOR PEOPLE WHO HAVE ALZHEIMER DISEASE, RELATED DEMENTIAS, AND MEMORY LOSS* 259 (5th ed. 2011); PECK & LAW, *supra* note 12, at 57; Blank, *supra* note 50; Fox et al., *supra* note 11, at 69. Decisional capacity to appoint a proxy or create an advance directive likely still exists in early dementia. Coll, *supra* note 41, at 381–82.

67. PECK & LAW, *supra* note 12, at 51, 55–56 (describing cases of “wrongful resuscitation”); Davis, *supra* note 4, at 745 (describing cases when advance directives were not followed); Sinoff & Blaja-Lisnic, *supra* note 61, at 100. Some attorneys do not consider that people may want everything possible done to prolong their lives and instead provide specific guidance on how to customize advance planning forms to ensure that death is hastened for persons with dementia. PECK & LAW, *supra* note 12, at 73–74.

68. See, e.g., Norman L. Cantor, *On Avoiding Deep Dementia*, 48 HASTINGS CTR. REP., July–Aug. 2018, at 15; Menzel & Steinbock, *supra* note 5; Menzel & Chandler-Cramer, *supra* note 39; Thaddeus Pope & Bernadette J. Richards, *Decision-Making: At the End of Life and the Provision of Pretreatment Advice*, 12 J. BIOETHICAL INQUIRY 389 (2015).

69. Schindler & Waksman, *supra* note 58, at 354; Kuldeep N. Yadav et al., *Approximately One in Three US Adults Completes Any Type of Advance Directive for End-of-Life Care*, 36 HEALTH AFF. 1244 (2017).

person as well as a default set of standards of surrogate decisionmaking. In the absence of an advance directive, surrogates are eligible in a hierarchy that favors immediate family members, but may also include friends or other parties after family.<sup>70</sup> In order to respect the patient's autonomy, surrogates are generally required to make a substituted judgment, or to decide as the incapacitated person would decide if they were competent.<sup>71</sup> Failing information about values and preferences that would guide a substituted judgment, a best interests standard is used.<sup>72</sup>

## 2. Guardianship and Dementia

When a court finds a person is incompetent to make decisions, a guardian may be appointed and given the power to make at least some (and perhaps all) decisions on their behalf.<sup>73</sup> The justification for guardianship, a significant liberty infringement, is that the state is obligated "to protect those who are incapable of dealing with their own affairs."<sup>74</sup> There may be a point in the progression of dementia that a person experiences "such a profound decline in [their] cognition that [they are] deemed globally incapacitated. In this event, the patient may warrant the appointment of a legal guardian."<sup>75</sup>

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70. Winsor C. Schmidt, *Proxy Decision-Making: A Legal Perspective*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 311, 315 (describing problems when a physician is the surrogate decisionmaker and incorrectly assesses their patient's quality of life).

71. See, e.g., UHCDA, *supra* note 2, at prefatory note. The problems with attempting to make a substituted judgment are well documented. For example, there is often discordance between what the surrogate decides and what the patient wants. Sinoff & Blaja-Lisnic, *supra* note 61, at 97, 99, 100–01. There also may be discordance between what the patient wanted while competent and what they want when incapacitated. Ofra G. Golan, *End-of-Life Care*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 393, 416.

72. How best interests are determined is often unclear, however, and leaves room for value judgements from surrogates and physicians. Sinoff & Blaja-Lisnic, *supra* note 61, at 101; see also JONATHAN HERRING, RELATIONAL AUTONOMY AND FAMILY LAW 45–46 (2014) (describing the indeterminacy of best interests tests in other contexts); Dresser, *Life, Death, and Incompetent Patients*, *supra* note 3, at 395–97 (describing how others' interests are sometimes incorporated into the best interests analysis). The Uniform Health Care Decisions Act ("UHCDA") directs the surrogates making a best interests determination to "consider the principal's personal values to the extent known to the agent," but "does not prescribe a detailed list of factors for determining the principal's best interest but instead grants the agent [or surrogate] discretion to ascertain and weigh the factors likely to be of importance to the principal." UHCDA, *supra* note 2, at § 2(e), 9.

73. MARSHALL B. KAPP, THE LAW AND OLDER PERSONS: IS GERIATRIC JURISPRUDENCE THERAPEUTIC? 12–15 (2003) (describing guardianship); Diller, *supra* note 11, at 500–10 (describing guardianship and recent reforms); Kohn et al., *supra* note 13, at 1116; Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

74. Schindler & Waksman, *supra* note 58, at 353; KAPP, *supra* note 73, at 12–15; Diller, *supra* note 11, at 502; Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U. L. REV. 527, 560 (2009).

75. Coll, *supra* note 41, at 382. Books for caregivers of persons with dementia often discuss guardianship. See, e.g., KENNY, *supra* note 36, at 82–83.



Many have expressed concerns about the use of plenary guardianships, which strip persons placed under guardianship of all decision-making authority.<sup>76</sup> One concern is that guardians may not receive training or be licensed,<sup>77</sup> which means guardians may not know how best to fulfill their responsibilities to their ward.<sup>78</sup> Another concern is the negative psychological effects that can stem from being under guardianship, especially when guardians do not consider their ward's current values and preferences,<sup>79</sup> which guardians may not be required to do.<sup>80</sup>

More importantly, however, guardians may be assigned with only minimal investigation of the extent of a ward's decision-making abilities, and there are alternatives to plenary guardianship that could preserve decision-making authority for persons with impaired cognition. For example, guardianship can be limited to specific decision-making domains (e.g., finances) instead of all decisions, or a healthcare proxy can be appointed.<sup>81</sup> Relatedly, with conditions such as dementia, it is not clear at what point in the trajectory of the degenerative illness a guardian may be warranted, if ever, as the person likely retains at least some decision-making ability.<sup>82</sup>

### C. Healthcare Decisionmaking and Dementia

It is important to understand how persons with dementia prefer to make healthcare decisions and their healthcare decision-making experiences before

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76. Kanter, *supra* note 74, at 560; Kohn et al., *supra* note 13, at 1117–20 (summarizing critiques of guardianship).

77. Schmidt, *supra* note 70, at 315.

78. *Id.* at 318.

79. Kohn et al., *supra* note 13, at 1119–20.

80. The Uniform Guardianship, Conservatorship, and Other Protective Proceedings Act directs guardians to include the person under guardianship in decisionmaking and to decide on the basis of wards' preferences and goals. UNIF. GUARDIANSHIP, CONSERVATORSHIP, & OTHER PROTECTIVE PROCEEDINGS ACT, § 313(b)(2) (NAT'L CONFERENCE COMM'RS UNIF. STATE LAWS 2017) [hereinafter UGCOPPA]. This is only a model law, however, and some courts have interpreted their state guardianship statutes that reference substituted judgment to refer only to the "preferences of the ward that were 'previously expressed'—i.e., before the ward became incompetent." Estate of K.E.J. v. K.E.J., 887 N.E.2d 704, 721 (2008). This means that the "[ward's] current desire . . . even if it were clearly and consistently expressed over the course of the proceedings . . . [does] not automatically trump all other considerations." *Id.*

81. Tailored guardianship was created to respect the decision-making abilities a person retains but is not often used. Margaret Isabel Hall, *Dementia, Autonomy and Guardianship for the Old*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 339; Schindler & Waksman, *supra* note 58, at 353–54. But see PECK & LAW, *supra* note 12, at 232 ("Most states tend to impose the least restrictive guardianship or conservatorship as is necessary to maintain the well-being of the incapacitated person so as to preserve as many rights of the incapacitated person as possible."); Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity*, 39 AM. J. L. & MED. 134, 156–57 (2013) (recommending limited financial guardianships).

82. KENNY, *supra* note 36, at 80; Coll, *supra* note 41, at 383; Jennings, *supra* note 62, at 446; Schindler & Waksman, *supra* note 58, at 353.

assessing whether healthcare decision-making laws should change. This Section first summarizes the empirical literature on healthcare decision-making abilities and preferences, and then describes the experience of healthcare decisionmaking for persons with dementia.

*1. Healthcare Decision-making Abilities and Preferences of Persons with Dementia*

While dementia results in impaired cognition, persons with dementia may retain decision-making abilities for years after a dementia diagnosis. Indeed, a meta-analysis of studies of decisionmaking concludes that “a diagnosis of dementia does not imply incapacity.”<sup>83</sup> Rather, research has shown that persons with dementia—even in the moderate to severe stages of dementia—can “reliably report on their care values and preferences, well-being, and quality of life.”<sup>84</sup> However, research on AD, the most common type of dementia, has found that the capabilities of persons with dementia are not always recognized or accommodated, even by individuals closest to the person with dementia.<sup>85</sup> Ignorance of their remaining abilities may not matter if persons with dementia do not desire to retain autonomy, but this is often not the case.

While there are no systematic studies of healthcare decision-making preferences of persons with MCI or dementia, there have been multiple smaller studies.<sup>86</sup> These studies consistently reveal that, on the whole, persons with MCI or mild dementia strongly prefer to be involved in decisions

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83. Fetherstonehaugh et al., *supra* note 61, at 144.

84. Miller et al., *supra* note 8, at 1142–43; *see also* James M. Wilkins, *Dementia, Decision Making, and Quality of Life*, 19 AM. MED. ASS’N J. ETHICS 637, 637 (2017). Some books targeted to family members and caregivers of persons with dementia also recognize that persons with dementia can communicate about their preferences. *See, e.g.*, JOY A. GLENNER ET AL., *WHEN YOUR LOVED ONE HAS DEMENTIA: A SIMPLE GUIDE FOR CAREGIVERS* 18 (2005).

85. *See, e.g.*, Steven R. Sabat, *Selfhood and Alzheimer’s Disease*, in *THE PERSON WITH ALZHEIMER’S DISEASE*, *supra* note 10, at 88, 89.

86. Miller et al., *supra* note 8, at 1144 (reviewing all the literature on dementia and decision-making).

Compared to the corpus of scientific and medical studies of dementia, there are relatively few studies that examine the preferences and experiences of persons with dementia. Phinney, *supra* note 10, at 49; Young, *supra* note 10, at 29. As one scholar remarked, “For a long time there seems to have been a largely implicit assumption that people with dementia were not able to express their own views in a way which made it appropriate to ask them.” Hugh Series, *The Happy Dementia Patient*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 105. This assumption may be because medicalizing dementia “portrays dementia as a disease which steadily erodes the brain, leaving the physical shell of a person lacking the inner machinery of the person. . . . The shell becomes an object of care and study, but not a person to be consulted.” *Id.* at 106. Or this assumption could be due to a cultural or philosophical belief that personhood is related to cognitive ability. Once an individual is thought to lack decisional capacity, they become a “non-person,” and “there is no point in asking [a nonperson] about its experiences and beliefs.” *Id.*; *see also* BEARD, *supra* note 18, at 109–10 (finding that when people received a diagnosis of MCI or dementia, clinicians began talking to their family instead of talking to them).

about their lives, rather than have others make decisions on their behalf.<sup>87</sup> Persons with early dementia know that their decision-making abilities will decline over time, but desire to remain independent and feel capable for as long as possible.<sup>88</sup> They want to share in healthcare decisionmaking with their family members and physicians,<sup>89</sup> but they also want others to respectfully provide support instead of taking over.<sup>90</sup> Persons with dementia often convey frustration with not being acknowledged as having the capacity to think rationally, and with not having their preferences and decisions respected. As one man with AD told researchers:

Sometimes, I'm about to say something that is very important to me and it's nearly impossible to transmit the information because everyone listening has the presumption that what I'm about to say is unscrewed. There's essentially no way for me to convince anybody that although I'm affected by Alzheimer's in many ways, there's still a lot that's up there in my mind that has reason to be communicated!<sup>91</sup>

Knowledge of decision-making preferences, coupled with the fact that dementia is not, at least initially and for some period of time in the progression of the disorder, completely incapacitating, has resulted in calls for clinicians to assist their patients with dementia in maintaining independence.<sup>92</sup> Additionally, clinicians are advised "to reduce the excess disability commonly encountered in dementia as a result of fear and stigma . . . [and] recognize that people with dementia, alongside their families, are active agents who seek to cope with and manage their illness."<sup>93</sup>

## 2. Healthcare Decision-making Experiences

As recent studies have demonstrated, when persons with dementia are not prevented from making or participating in their own healthcare decisions, they are able to maintain self-esteem and have enhanced wellbeing.<sup>94</sup> As one research participant with dementia stated:

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87. BEARD, *supra* note 18; Fetherstonehaugh et al., *supra* note 61; Wilkins, *supra* note 84, at 637. There is, of course, variability in decision-making preferences. Some persons with dementia may be perfectly content with having others make decisions on their behalf.

88. Fetherstonehaugh et al., *supra* note 61, at 147–48 (noting also that persons with dementia come up with ways to compensate for their acquired impairments).

89. Miller et al., *supra* note 8, at 1145, 1150. This is also consistent with other findings about late-life decision-making preferences. Wright, *supra* note 20.

90. Fetherstonehaugh et al., *supra* note 61, at 146–47.

91. Lisa Snyder, *Social and Family Relationships: Establishing and Maintaining Connections*, in *THE PERSON WITH ALZHEIMER'S DISEASE*, *supra* note 10, at 112, 115.

92. Noa Bregnan & Orna Moore, *Clinical Management of Dementia: An Overview (I)*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 45. Indeed, healthcare decision-making law also supports independent decisionmaking, absent a finding of incapacity.

93. Fox et al., *supra* note 11, at 75.

94. Miller et al., *supra* note 8, at 1151.

I feel more settled and okay in myself. That I'm still doing things and capable. To have still some independence in there. That I am still here, and I do have a say, and I'm not just a person with dementia and ignored, and that everybody else knows more than me. To still understand that there is a person there, and being aware of what stage I'm at, and what I can still input and allow that to happen.<sup>95</sup>

Another research participant commented:

I feel like I'm part of the decision, even though I know probably now I'm not contributing a great deal, at least I feel as if I'm part of the decision. And that's very, very important. So I feel enabled and empowered, even though each year goes by I'm less participating, at least I feel as if I am.<sup>96</sup>

Unfortunately, despite evidence that persons with dementia prefer to participate in decisionmaking (and despite emerging best clinical practices for interacting with patients with dementia meant to recognize and respect their agency), many patients with dementia report unhappiness and dissatisfaction in their healthcare encounters.<sup>97</sup> Patients report that once they are diagnosed with MCI or dementia, their healthcare providers no longer communicate with them, and may not even tell them their diagnosis.<sup>98</sup> Instead, clinicians talk to their family members to convey and collect information about the patient's experience with dementia.<sup>99</sup> One patient with AD reported, "My doctor asks me how I am, nods when I tell him, and then asks me to step outside. He and my wife discuss me and then call me back and tell me what to do."<sup>100</sup> Another patient noted that, "People talk *about* me, *around* me, but don't talk *to* me."<sup>101</sup> This exclusion from healthcare decisionmaking, even for minor or routine decisions,<sup>102</sup> is contrary to the deci-

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95. Fetherstonehaugh et al., *supra* note 61, at 148.

96. *Id.*

97. BEARD, *supra* note 18; Phinney, *supra* note 10; WORLD HEALTH ORG., *supra* note 27, at 84. This seems to be a common experience of persons with disability in healthcare settings. Elizabeth Pendo, *What Patients with Disabilities Teach Us About the Everyday Ethics of Health Care*, 50 WAKE FOREST L. REV. 287, 292–96 (2015).

98. BEARD, *supra* note 18, at 12; Phinney, *supra* note 10, at 73 ("Several participants told me that their doctors did not listen to them . . ."); Young, *supra* note 10, at 39.

99. Young, *supra* note 10, at 39, 42. For illustrative anecdotes about how some physicians do not recognize the personhood of their patients with dementia while some physicians still engage their patients with dementia in informed consent conversations, see POWELL, *supra* note 4, at 11–12.

100. Young, *supra* note 10, at 40.

101. Fetherstonehaugh et al., *supra* note 61, at 148.

102. *Id.* at 144 ("Despite strong indications within the literature that people with dementia are willing and able to participate in decision making, participation is often denied, sabotaged or tokenistic."); Miller et al., *supra* note 8, at 1144–45; James M. Wilkins, *Narrative Interest Standard: A*

sion-making preferences of many persons with dementia, and leads to feelings of marginalization and resentment towards family members and physicians.<sup>103</sup>

It is reasonable to assume that persons with dementia are excluded from participating in healthcare decisions because their dementia has progressed to the point that they are incapable of expressing what is important to them or making a choice (i.e., they fail at least one part of a formal capacity assessment). There is empirical evidence, however, that patients are excluded from healthcare decisionmaking even when they have decisional capacity.<sup>104</sup> One scholar observed, “[I]n some cases it appeared that doctors were inclined to conclude that a person lacked capacity simply because [they] had dementia.”<sup>105</sup> Others have noted, “It is . . . customary in healthcare settings to rely upon family members to make treatment and long-term care decisions for persons with dementia, regardless of whether legal or medical channels have formally established incapacity to make decisions.”<sup>106</sup>

Studies reveal several reasons why persons with dementia are prevented from making or participating in decisions that affect their lives. First, persons with dementia may be viewed as incapable of making good decisions.<sup>107</sup> That is, those with an interest in the wellbeing of the person with dementia, such as family members and physicians, may fear that because dementia ad-

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*Novel Approach to Surrogate Decision-Making for People with Dementia*, 58 GERONTOLOGIST 1016, 1017 (2018).

There is variation in decision-making experiences, however. Studies show that the degree to which the person with dementia participates in decisionmaking depends on the stage of dementia, level of impairment, educational background, gender, and relationship type with their surrogates. Miller et al., *supra* note 8, at 1146–48.

103. Fetherstonehaugh et al., *supra* note 61, at 148; Young, *supra* note 10, at 40–41.

104. Indeed, studies have shown that clinicians sometimes attempt to remove decision-making authority from their patients and instead choose what they think is in their patient’s best interests. This occurs not after a formal finding of incapacity, but rather “on the basis of history, diagnosis, disability, age, appearance, behaviour or the fact that someone was making an unwise decision.” Hugh Series, *Best Interests Determination: A Medical Perspective*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 85, 91.

105. *Id.* at 92. That is, “inability to manage one’s own independence and care was confused with inability to make a decision.” *Id.* Studies have also revealed that physicians do not know how to assess capacity and determine whether a surrogate decisionmaker needs to be consulted for their patient. Schmidt, *supra* note 70, at 315.

106. Miller et al., *supra* note 8, at 1142. It is important to emphasize that this custom is contrary to healthcare decision-making law, which requires a determination of incapacity before others are legally authorized to make decisions for an individual without their consent. See UHCDA, *supra* note 2, at 5(a).

107. Woods & Pratt, *supra* note 62, at 424. Some research has shown that healthcare providers may assume their older patients are incapable of making decisions. Cheryl Dellasega et al., *Commentary: Decision-Making Capacity in the Acutely Ill Elderly*, in OLDER ADULTS’ DECISION-MAKING AND THE LAW 142, 152 (Michael Smyer et al. eds., 1996).

versely affects cognition, the person will, without full understanding or intention, make decisions counter to their own wellbeing.<sup>108</sup> In order to combat this possibility, others take over the decisionmaking for the person with dementia, even if the person with dementia still has capacity.<sup>109</sup>

Second, family members may not realize how important remaining independent in healthcare decisionmaking is to the person with dementia.<sup>110</sup> Or, the family members may understand, but discount the values and preferences of the person with dementia because they desire to control decisionmaking,<sup>111</sup> perhaps because the decisions impact themselves or other family members.

Third, family members may know that the person with dementia is capable of and wants to be involved in decisionmaking, and may even support their loved one in retaining decision-making authority, but are nonetheless pressured by healthcare providers to take over decisionmaking.<sup>112</sup> Relatedly, healthcare providers may be under the mistaken impression that a dementia diagnosis requires that surrogates make decisions rather than the patient.<sup>113</sup>

In sum, the experience of healthcare decisionmaking often does not accord with the capabilities and preferences of persons with mild to moderate dementia, which leads to a decrease in their wellbeing. Indeed, the majority of persons with dementia are “in the earlier years . . . [and] are perfectly able both to experience joy and to suffer when they are no longer treated as full persons.”<sup>114</sup>

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108. Indeed, a central tension surrounding debates about dementia and decisionmaking is how to balance safety and freedom. POWELL, *supra* note 4, at 161, 167, 204, 213, 235, and 237. Recent research in nursing homes has demonstrated that nurses value safety more than honoring patient preferences because they worry about lawsuits or administrative sanctions. Liza L. Behrens, Nursing Staff Perceptions of Risk When Honoring Nursing Home Residents’ Preferences: A Sequential Focus Group Study (June 11, 2019) (unpublished Ph.D. dissertation, Penn State University) (on file with author).

109. Woods & Pratt, *supra* note 62, at 424 (“[I]t is the perception of others that the person with dementia lacks insight that leads to a lack of respect, or at least a willingness to overrule, the person’s autonomy . . .”). Family members may also take over decisionmaking if they consume books targeted toward caregivers that advise them to do so. *See, e.g.*, GLENNER ET AL., *supra* note 84, at 24–25; KENNY, *supra* note 36, at 57–76 (describing the person with dementia as “mute”).

110. Miller et al., *supra* note 8, at 1146.

111. *Id.* at 1146, 1150.

112. *Id.* at 1148.

113. *Id.* at 1150 (“Case managers also felt it was their legal duty to focus on the decision of the individual who was named as a surrogate decision-maker and even exclude the person with dementia from the conversation . . .”).

114. Powell, *supra* note 57, at S72.

## II. LAWS SHOULD NOT PREVENT PERSONS WITH DEMENTIA FROM PARTICIPATING IN HEALTHCARE DECISIONS

As Part I explains, persons with dementia prefer to make or at least participate in decisions about their healthcare but are routinely marginalized in or excluded from healthcare decisionmaking, both by family members and healthcare providers. Such marginalization and exclusion disregard their autonomy interests, impede their self-determination, and decrease their wellbeing. If respect for autonomy and increased wellbeing are valued social goods, then persons with dementia should not be prevented from participation in healthcare decisionmaking. Because the law of surrogate healthcare decisionmaking facilitates this marginalization and exclusion, this Part describes why the law should change.

### A. *Preventing Persons with Dementia from Participating in Healthcare Decisionmaking Is Inconsistent with Respect for Autonomy*

The law and ethics of healthcare decisionmaking are based on respect for autonomy.<sup>115</sup> This is not only because of the traditional centrality of autonomy in all areas of law,<sup>116</sup> but also because autonomy is especially important in healthcare decisionmaking.<sup>117</sup> It is in this context that decisions are made about what happens to one's body, and some of these decisions concern the continuation of life. Because only one person bears the corporeal consequence of the healthcare decision, it is fairly uncontroversial to argue that this person should be the one to decide.<sup>118</sup>

When an individual has impaired cognition, which could affect their ability to be autonomous, efforts are made to respect the individual's precedent autonomy, if any, by relying on advance directives or other evidence of past preferences and values.<sup>119</sup> This decision-making process is required by law.<sup>120</sup> Because dementia results in cognitive impairment, and is commonly viewed as incompatible with autonomous decisionmaking,<sup>121</sup> healthcare providers and family members may exclude persons with dementia from

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115. See Wright, *supra* note 20, at 1064.

116. Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives*, 37 VILL. L. REV. 1705, 1706–08 (1992).

117. See Wright, *supra* note 20. Recent scholarship has noted that enhancing patient agency and autonomy is good for their health. MARK D. SULLIVAN, *THE PATIENT AS AGENT OF HEALTH AND HEALTH CARE* (2017).

118. Dresser, *supra* note 59, at 400 (“It was the patients who would be most affected by the treatment decision; thus, they should be permitted to choose for themselves.”); WORLD HEALTH ORG., *supra* note 27, at 45.

119. See UHCDA, *supra* note 2.

120. *Id.*

121. But see Jaworska, *supra* note 4, at 109 (“[M]any of these patients may still be capable of autonomy to a significant degree . . .”).

healthcare decisionmaking or override their current wishes, and yet understand their actions as surrogates as respectful of the (prior) autonomy of the person with dementia.<sup>122</sup>

But the symptoms of MCI or early dementia may not result in cognitive impairments significant enough to eradicate present autonomy, or trigger use of a surrogate under healthcare decision-making law.<sup>123</sup> Many persons with dementia should then retain their legal right to make their own healthcare decisions. But, as discussed earlier, there is evidence that physicians exclude patients with dementia from the decision-making process even when their patients have decisional capacity.<sup>124</sup> Importantly, studies also show that capacity may not even be assessed, but instead incapacity may be presumed solely due to the diagnosis of dementia.<sup>125</sup> The law of surrogate decisionmaking facilitates this exclusion because it defers to physician's judgment on whether their patient has decisional capacity. Change is thus required so that persons who retain decision-making capabilities are ensured of their legal right to make their own healthcare decisions.

Given the centrality of the principle of respect for autonomy to healthcare decision-making law and clinical practice, it is also necessary to critically examine whether the conceptualization of autonomy in law, medicine, and bioethics works in practice. This Article argues that the traditional understanding of autonomy is both inaccurate and incomplete, and when applied to persons with dementia, disrespects their present (i.e., contemporaneous) autonomy.

Indeed, empirical research demonstrates that traditional notions of autonomous decisionmaking<sup>126</sup> are inaccurate. Behavioral economics research reveals that decisionmaking is distorted by cognitive biases,<sup>127</sup> and that people are therefore capable only of "bounded rationality."<sup>128</sup> Psychological research also demonstrates that many decisions are not made rationally but,

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122. See *supra* Section I.C.

123. For example, persons with dementia may forget people's names or be unable to adequately manage their finances but be found to possess healthcare decision-making capacity. See generally *supra* Sections I.A, I.B.1. But see Jaworska, *supra* note 4, at 109 (arguing that the emphasis on decision-making capacity to determine whether someone is autonomous is misguided, and the relevant question about whether a person with dementia is autonomous is whether they have the capacity to value).

124. See Series, *supra* note 86, at 105.

125. Miller et al., *supra* note 8, at 1142; Series, *supra* note 86, at 105. Presumptions of incapacity at any stage of dementia will translate into an unnecessary loss of autonomy. Woods & Pratt, *supra* note 62, at 426.

126. See BEAUCHAMP & CHILDRESS, *supra* note 23, at 104–05.

127. See, e.g., DANIEL KAHNEMAN, THINKING, FAST AND SLOW (2011); RICHARD H. THALER & CASS R. SUNSTEIN, NUDGE: IMPROVING DECISIONS ABOUT HEALTH, WEALTH, AND HAPPINESS 23–37 (2009).

128. Russell Korobkin, *Three Choice Architecture Paradigms for Healthcare Policy*, in NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS 15 (I. Glenn Cohen et al. eds., 2016).



rather, are made on the basis of emotions.<sup>129</sup> Furthermore, philosophers and social scientists have demonstrated that many people cannot make decisions that promote their interests because not all desirable options are available due to structural conditions such as poverty. That is, even if perfect rationality is possible, people still may not be fully self-determining or autonomous given limited options.<sup>130</sup> In the healthcare setting, autonomous decisionmaking is even more difficult because patients are in a vulnerable physical or mental state; there is a higher cognitive burden to understand complex medical information; and there is a relationship of power and dependence between healthcare providers and their patients.<sup>131</sup> Thus, it is more accurate to describe decisionmaking by persons without cognitive impairments as *agentic* rather than autonomous.<sup>132</sup>

The dominant understanding of autonomy as individualistic also does not accord with lived experience. Feminist philosophers, disability studies scholars, and social scientists have advanced the concept of relational autonomy,<sup>133</sup> which recognizes that autonomy occurs (or is thwarted) in interactions with others. Recent legal scholarship has also demonstrated that individuals making healthcare decisions at the end of life understand autonomous decisionmaking as relational in nature.<sup>134</sup> Specifically, people often prefer to consult and collaborate in healthcare decisions with others, such as family members and physicians, and may also make decisions on the basis of other's interests.<sup>135</sup> As I have argued elsewhere,<sup>136</sup> the concept of autonomy in

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129. See Jonathan Herring, *Best Interests and Dementia*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 301, 304.

130. Sherwin, *supra* note 24, at 13–14.

131. See generally NUDGING HEALTH: HEALTH LAW AND BEHAVIORAL ECONOMICS, *supra* note 128. Indeed, using informed consent as the standard of autonomous decisionmaking demonstrates how often healthcare decisions are not autonomous. SCHNEIDER, *supra* note 61, at xi–xii. Sometimes patients do not even perceive that they have made a choice. Theresa S. Drought & Barbara A. Koenig, “Choice” in *End-of-Life Decision Making: Researching Fact or Fiction?*, 42 GERONTOLOGIST 114, 121 (2002).

132. Agency for the purposes of this Article means “an individual is free to exercise . . . choice, even if the choice is from a limited set of options” or is made without full understanding. See Dara E. Purvis, *The Rules of Maternity*, 84 TENN. L. REV. 367, 375 (internal quotation marks omitted) (describing autonomy and defining agency); see also STEVEN R. SABAT, *ALZHEIMER’S DISEASE & DEMENTIA: WHAT EVERYONE NEEDS TO KNOW* 181 (2017) (“Agency refers to a person’s feelings of control . . . and it involves the benefits of making choices . . .”). This definition of agency aligns with the definition of autonomy found in the Convention on the Rights of Persons with Disabilities. United Nations Convention on the Rights of Persons with Disabilities, art. 3(a), Dec. 13, 2006, 2515 U.N.T.S. 44910 (noting autonomy “includ[es] the freedom to make one’s own choices.”).

133. JENNIFER NEDELSKY, *LAW’S RELATIONS: A RELATIONAL THEORY OF SELF, AUTONOMY, AND LAW* 19–89 (2011); Harold Braswell, *Can There Be a Disability Studies Theory of “End-of-Life Autonomy?”* 31 DISABILITY STUD. Q. 4 (2011), <http://dsq-sds.org/article/view/1704/1754>; Carolyn Ells, *Lessons About Autonomy from the Experience of Disability*, 27 SOC. THEORY & PRAC. 599, 600 (2001); Purvis, *supra* note 132, at 374–77; Sherwin, *supra* note 24.

134. Wright, *supra* note 20, at 1066–67, 1093, 1137.

135. *Id.* at 1081–94.

136. *Id.* at 1066–68.

healthcare decision-making law requires revision to reflect its relational nature.

If the decision-making abilities of persons with dementia are assessed with respect to the ideal, atomistic conceptualization of autonomy, this almost ensures that persons with dementia will be deemed incapable of autonomy, and a surrogate will be used for healthcare decisions. But if the decision-making abilities of persons with dementia are compared to those of persons with typical cognitive abilities, it is not at all clear that persons with dementia should be prevented from making their own decisions. Again, dementia is not globally incapacitating in its earlier stages, and people retain significant capabilities despite the onset of cognitive impairments.<sup>137</sup> Research also has demonstrated that persons with MCI or early dementia have the ability to decide agentically, on the basis of their interests, to the same extent as persons without dementia.

Thus, in the healthcare setting, where assistance with decisionmaking is preferred by both patients with and without dementia,<sup>138</sup> and where both kinds of patients will struggle to fully understand the decisions they make,<sup>139</sup> it is both logical and ethical to use the same decision-making standard for all patients. Applying the principle of equality could mean that no one is permitted to make their own healthcare decisions, returning to a time of physician paternalism. This Article argues instead that all patients should be permitted to make their own healthcare decisions.

To conclude, if autonomous decisionmaking is reconceptualized as *agentical* and *relational* decisionmaking, it becomes clear that many persons with MCI and mild to moderate dementia retain autonomy and should, therefore, not be prevented from making their own healthcare decisions at the time they need to be made.<sup>140</sup> How autonomy in law is understood and applied thus should change, so that persons with dementia can participate in

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137. Bruce Jennings, *Agency and Moral Relationship in Dementia*, 40 METAPHILOSOPHY 425, 430 (2009) (“Semantic agency refers to the capacity to communicate . . . with others, and to evince understanding and evaluation of such communication . . . this capacity persists in properly structured, supportive caregiving environments even when high-level cognitive, speech, executive, and short-term memory functioning have been impaired.” (emphasis omitted)).

138. Miller et al., *supra* note 8, at 1145, 1150; Wright, *supra* note 20.

139. SCHNEIDER, *supra* note 61, at 144; Jennifer Moye et al., *Capacity to Consent to Treatment: Empirical Comparison of Three Instruments in Older Adults with and Without Dementia*, 44 GERONTOLOGIST 166, 172 (2004) (finding that persons with mild dementia, although impaired, have the capacity to make healthcare decisions).

140. Other scholars distinguish between agency (i.e., participation in decisionmaking) and autonomy in the context of dementia and decisionmaking. Miller et al., *supra* note 8, at 1145–46. The problem with this distinction is that it assumes that autonomy is possible at all.

healthcare decisionmaking to the extent that they desire and are able.<sup>141</sup> Retaining autonomy will likely also result in increased wellbeing for persons with dementia.<sup>142</sup>

*B. In Order to Increase Wellbeing, Laws Should Match the Preferences of Persons with Dementia*

Prominent health law scholars, bioethicists, and healthcare organizations have argued that laws affecting patients should account for patients' preferences and interests.<sup>143</sup> Such consideration may make it more likely that laws enhance, or at least do not diminish, the wellbeing of persons subject to them.<sup>144</sup> Healthcare decision-making laws, and proposals to change these laws, therefore should take into account the perspectives and interests of persons with dementia.<sup>145</sup>

Presently, however, much of the recent scholarly discussion about laws that impact persons with dementia is dominated by nondisabled persons who fear and abhor the prospect that they will acquire dementia in the future.<sup>146</sup> Indeed, scholarship and legal advice about dementia tends to focus on how

141. Respect for the agency of persons with dementia would also mean respecting the decision of some persons to defer to others.

Additionally, when it comes to decisions about, for example, where to live or whether to drive, there may be greater negative effect on others than with respect to healthcare decisionmaking (the effects of which are internalized to a greater degree). In the former instances, other's interests need to be considered, and the decision of the person with dementia may be challenged. See POWELL, *supra* note 4, at 243 (describing risks of harm to self and others when persons with dementia drive); Woods & Pratt, *supra* note 62, at 428 ("Where the risks are perceived as being to others, not just to the person with dementia, then autonomy is most likely to be overruled . . .").

142. Fetherstonehaugh et al., *supra* note 61, at 143.

143. Alicia Hall, *Making Good Choices: Toward a Theory of Well-being in Medicine*, 37 THEORETICAL MED. & BIOETHICS. 383, 394 (2016) ("[A]ny well-being policy can be justified only if it is based on the values of those people whose well-being the policy intends to foster."); Mark A. Hall et al., *Rethinking Health Law*, 41 WAKE FOREST L. REV. 341, 342 (2006) (arguing that "the central purpose of healthcare law is to improve the lives of patients"); Lois Shepherd & Mark A. Hall, *Patient-Centered Health Law and Ethics*, 45 WAKE FOREST L. REV. 1429, 1433 (2010) ("[L]aw that affects patients should better take into account what it means to be a patient.").

144. The legal perspective that considers law's effects on psychological wellbeing is known as therapeutic jurisprudence. See, e.g., David B. Wexler & Bruce J. Winick, *Therapeutic Jurisprudence as a New Approach to Mental Health Law Policy Analysis and Research*, 45 U. MIAMI L. REV. 979 (1991).

145. Rebecca Dresser, *Advance Directives and Discrimination Against People with Dementia*, 48 HASTINGS CTR. REP., July–Aug. 2018, at 26 ("[P]eople with the condition should be represented in the debate over treatment standards."); WORLD HEALTH ORG., *supra* note 27, at 4, 37 ("People with dementia . . . often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them."). Further, experts on elder law have also emphasized the need for law that applies to older persons to enhance their wellbeing. KAPP, *supra* note 73.

146. See, e.g., Cantor, *supra* note 68; Menzel & Chandler-Cramer, *supra* note 39.

to avoid living with it.<sup>147</sup> For example, some scholars argue that physician aid in dying laws should be changed to permit persons with advanced dementia to access this end-of-life option.<sup>148</sup> Additionally, scholars also publish articles advising how to tailor advance directives to direct others not to provide assistance with eating or drinking in the event of dementia, which if followed will hasten death.<sup>149</sup>

Privileging the arguments of persons without dementia, who have largely negative views of the disability, may make formulating law and policy that can promote what is actually good for persons with dementia difficult.<sup>150</sup> To better promote the wellbeing of persons with dementia, the perspectives, experiences, and interests of those with dementia should instead be prioritized.<sup>151</sup>

Studies have demonstrated that when persons with dementia are prevented from making decisions, they are unhappy because they want to be involved in decisionmaking, and that conversely, being involved in decisionmaking and feeling agentic enhances their psychological wellbeing.<sup>152</sup> Because healthcare decision-making law is used to deny persons with dementia the opportunity to make healthcare decisions at the time the decision needs to be made—contrary to the preferences of many persons with dementia and

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147. See, e.g., Cantor, *supra* note 68; Menzel & Steinbock, *supra* note 5; Menzel & Chandler-Cramer, *supra* note 39; Pope & Richards, *supra* note 68.

148. Menzel & Steinbock, *supra* note 5. Persons who elect physician aid in dying in the United States are required to have decisional capacity at the time the request is made. Using an advance directive for physician aid in dying is impermissible. *Id.* at 484.

149. See, e.g., Menzel & Chandler-Cramer, *supra* note 39. There are notable exceptions, however. See, e.g., Dresser, *supra* note 145.

Advocacy organizations have also created and distributed such advance directives. See, e.g., JoNel Aleccia, “Aggressive” New Advance Directive Would Let Dementia Patients Refuse Food, KAISER HEALTH NEWS (Mar. 30, 2018), <https://khn.org/news/aggressive-new-advance-directive-would-let-dementia-patients-refuse-food/>.

150. Daniel Callahan, *Terminating Life-Sustaining Treatment of the Demented*, 25 HASTINGS CTR. REP., Nov.–Dec. 1995, at 25 (“The harder it is for us to imagine life as tolerable in such circumstances, the harder it will be to determine what is beneficial for the patient.”). What people fear when they think about a future with dementia is the severe, final stages. As some scholars have recently highlighted, however, there is a great deal of life to enjoy in the mild to moderate stages of dementia. POWELL, *supra* note 4, at 213.

151. As others have noted, “bioethicists have for too long had the power to set the terms of discussions about practices that primarily affect people with disabilities.” Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 GA. ST. U. L. REV. 893, 920 (2017). This is also consistent with the political demand from the disability rights community: “Nothing About Us Without Us!” *Id.*

152. See, e.g., Phinney, *supra* note 10; Young, *supra* note 10; see also SABAT, *supra* note 132, at 181 (2018) (describing link between agency and wellbeing); Melanie H. Mellers et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin’s Work on Gerontological Theory, Policy, and Practice*, 54 GERONTOLOGIST 67, 68–69 (2014) (describing positive association of control and increased wellbeing for older adults). Philosophers also note the link between autonomy and wellbeing. See, e.g., Jaworska, *supra* note 4, at 109 (“I associate potential for autonomy primarily with the capacity to value, and well-being with living in accordance with one’s values.”).

to the detriment of their wellbeing—it is necessary to think about ways to improve the legal regime governing healthcare decisionmaking for this population.

### III. SUPPORTED DECISIONMAKING AND DEMENTIA

Laws governing healthcare decisionmaking should ensure that persons, including those with dementia, who want to make their own healthcare decisions are able to do so. Law should also accommodate decision-making preferences for consultation or collaboration with others. With respect to these ends, healthcare decision-making law as often applied fails.

While healthcare decision-making law seems to be the most appropriate source for guidance about how healthcare decisions should be made for patients with decisional impairments, turning instead to other bodies of law actually may better respect the autonomy and promote the wellbeing of persons with dementia. An alternative model of decisionmaking that does not rely on surrogate decisionmakers for persons with impaired cognition, known as supported decisionmaking, can be found in state disability and guardianship law and can be beneficially applied to persons with dementia.<sup>153</sup>

This Article argues for widespread adoption of supported decision-making legislation, and also that persons with dementia should enter into these agreements with trusted supporters in order to assert their autonomy and make their own healthcare decisions. This Part begins by describing the concept of supported decisionmaking, and why this model is attractive to persons with disabilities and their advocates. It then describes existing supported decision-making laws in the United States. This Part concludes by discussing the application of supported decisionmaking to persons with dementia.

#### A. *Argument for Supported Decisionmaking*

Many disability advocates argue that to respect the civil and human rights of persons with cognitive impairments, such persons must remain free to make their own decisions instead of having this authority transferred to another person.<sup>154</sup> Both the Americans with Disabilities Act (“ADA”)<sup>155</sup> and Article 12 of the Convention on the Rights of Persons with Disabilities (“CRPD”)<sup>156</sup> support this argument.<sup>157</sup> For jurisdictions wishing to comply

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153. See *infra* Section III.B.

154. ANNA ARSTEIN-KERSLAKE, RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES: REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW (2017); GOODING, *supra* note 16; Kohn et al., *supra* note 13, at 1127.

155. 42 U.S.C. §§ 12101–12213 (2012).

156. United Nations Convention on the Rights of Persons with Disabilities, *supra* note 132, at art. 12.

157. *Id.*; Kohn et al., *supra* note 13, at 1118–19; Michael L. Perlin, “Striking for the Guardians and Protectors of the Mind”: The Convention on the Rights of Persons with Mental Disabilities and

with the principles embodied in disability law—particularly with the proclamation in the CRPD that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”<sup>158</sup>—supported decisionmaking is an attractive alternative to surrogate decisionmaking.<sup>159</sup>

Although there is no consensus on the definition of supported decisionmaking, generally it means that “an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual’s words and behavior to determine his or her preferences.”<sup>160</sup> Under this model, persons with disabilities retain legal authority to make their own decisions. Absent these laws and use of these agreements, persons with cognitive impairments may not be entitled under law to make their own decisions. Disability advocates argue that supported decisionmaking may lead to feelings of empowerment and better emotional, psychological, and physical wellbeing,<sup>161</sup> and thus this decision-making model should replace both guardianship and surrogate decisionmaking for persons with decisional impairments.

The supported decision-making relationship may be documented in a written agreement, which formalizes what most people do informally—consult with others in making decisions. As others have noted, this model of decisionmaking consists of “a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”<sup>162</sup> Thus, supported decisionmaking accords with the concept of relational autonomy.<sup>163</sup>

Supported decisionmaking for many persons with dementia is preferable to surrogate decisionmaking. Persons with dementia who enter these agreements retain legal capacity, regardless of their cognitive impairments. That is, they are decisionmakers whose choices must be respected by third parties. They therefore retain agency in healthcare decisionmaking, which is

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*the Future of Guardianship Law*, 117 PENN ST. L. REV. 1159 (2013); Salzman, *supra* note 73, at 197–220.

158. United Nations Convention on the Rights of Persons with Disabilities, *supra* note 132, at art. 12, ¶ 2.

159. Schindler & Waksman, *supra* note 58, at 355. Other scholars have argued, however, that “no amount of support will render every individual capable of making his or her ‘own’ decisions,” and so the system of surrogate decisionmaking remains important to protect vulnerable people. Hall, *supra* note 81, at 347–48 (arguing against supported decisionmaking for persons with dementia).

160. Kohn et al., *supra* note 13, at 1120.

161. *Id.* at 1127.

162. Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF, Winter 2012, at 8, 10.

163. See *supra* Section II.A.

consistent with their stated preferences to make or participate in decisions. As prior research has demonstrated, involvement in decisionmaking leads to increased wellbeing for persons with dementia.<sup>164</sup> Thus, supported decisionmaking has the potential to enhance both the relational autonomy and wellbeing of persons with mild to moderate dementia.

### *B. Supported Decision-making Laws in the United States*

A few jurisdictions in the United States have adopted supported decision-making legislation. Texas, in 2015, was the first state to do so.<sup>165</sup> Delaware, Wisconsin, the District of Columbia, Indiana, and Alaska have since passed supported decision-making legislation, and other states are currently considering adoption.<sup>166</sup> This Section describes the common elements of supported decision-making law in the United States.

#### *1. Terminology*

The terminology used to describe parties who enter into a supported decision-making agreement differs in each state's laws. While all use the word "supporter," the person with a disability is referred to as "adult with a disability" in Texas,<sup>167</sup> "principal" in Delaware and Alaska,<sup>168</sup> "adult with a functional impairment" in Wisconsin,<sup>169</sup> "supported person"/"adult with a disability" in the District of Columbia,<sup>170</sup> and "adult" in Indiana.<sup>171</sup> This Article refers to the person with a disability who enters into this agreement as the "principal," and those who agree to provide support as "supporters."

#### *2. Purpose*

The supported decision-making laws in Texas and Delaware start with a statement of the law's purpose.<sup>172</sup> In Texas, the purpose of the Act is "to recognize a less restrictive alternative to guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are

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164. See *supra* Section II.B.

165. Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973 (2018) (describing how fiscal conservatives and disability rights advocates supported this guardianship reform for different reasons).

166. Additionally, some states have built supported decisionmaking into very specific laws and regulations, such as those relating to organ transplantation decisions, for example, KAN. STAT. ANN. § 65-326 (2016); MD. CODE ANN. HEALTH GEN. § 20-1605 (LexisNexis 2015); OHIO REV. CODE ANN. § 2108.08(A) (LexisNexis 2017), or participation in managed or long-term care, for example, TENN. CODE ANN. § 71-5-1422; WASH. REV. CODE § 70.129.140.

167. See, e.g., TEX. EST. CODE ANN. § 1357.051 (West 2018).

168. See, e.g., DEL. CODE ANN. tit. 16, § 9403A(8) (2018); ALASKA STAT. § 13.56.020 (2018).

169. See, e.g., WIS. STAT. ANN. § 52.03 (West 2018).

170. See, e.g., D.C. CODE § 7-2131(13) (2019).

171. See, e.g., IND. CODE ANN. § 29-3-14-1 (West 2019).

172. Wisconsin, the District of Columbia, Indiana, and Alaska do not specify the purpose.

not considered incapacitated persons for purposes of establishing a guardianship under this title.”<sup>173</sup> Delaware has a much lengthier statement of purpose that describes supported decisionmaking in detail.<sup>174</sup> Delaware also directs that supported decisionmaking

be administered and interpreted in accordance with all of the following principles:

(1) All adults should be able to live in the manner they wish and to accept or refuse support, assistance, or protection as long as they do not harm others and are capable of making decisions about those matters.

(2) All adults should be able to be informed about and, to the best of their ability, participate in the management of their affairs.

(3) All adults should receive the most effective yet least restrictive and intrusive form of support, assistance, or protection when they are unable to care for themselves or manage their affairs alone.

(4) The values, beliefs, wishes, cultural norms, and traditions that an adult holds should be respected in managing an adult’s affairs.<sup>175</sup>

### 3. *Presumption of Capability*

Supported decision-making legislation in Delaware and Wisconsin directs that capacity is to be presumed for adults.<sup>176</sup> These state statutes and the Indiana and Alaska statutes also note that entering into a supported decision-making agreement is not evidence of incapacity to act outside of the agreement.<sup>177</sup> Indiana and Alaska direct that the principal who has a supported decision-making agreement is not required to use supporters and can act independently.<sup>178</sup>

### 4. *Eligibility Requirements for Supporters*

States may prohibit some people from acting as supporters. In Delaware and Alaska, employers or employees of the principal cannot be supporters,

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173. TEX. EST. CODE ANN. § 1357.003 (West 2018) (footnote omitted).

174. DEL. CODE ANN. tit. 16, § 9402A(a)(1)–(3) (2018).

175. *Id.* § 9402A(b)(1)–(4).

176. *Id.* § 9404A(a); WIS. STAT. ANN. § 52.03 (West 2018). This is consistent with the UHCDA, which states: “An individual is presumed to have capacity to make a health-care decision, to give or revoke an advance health-care directive, and to designate or disqualify a surrogate.” UHCDA, *supra* note 2, at 32. Texas, D.C., and Indiana do not have such provisions. Alaska states that “a principal is considered to have capacity even if the capacity is achieved by the principal receiving decision-making assistance.” ALASKA STAT. § 13.56.150(d) (2018).

177. DEL. CODE ANN. tit. 16, § 9404A(c); WIS. STAT. ANN. § 52.03; IND. CODE ANN. § 29-3-14-4(c) (West 2019); ALASKA STAT. § 13.56.150(c).

178. IND. CODE ANN. § 29-3-14-4(c); ALASKA STAT. § 13.56.150(b).



and neither can those who provide “paid support services,” unless these classes of persons are immediate family members of the principal.<sup>179</sup> Further, a supporter cannot be “[a]n individual against whom the principal has obtained an order of protection from abuse or an individual who is the subject of a civil or criminal order prohibiting contact with the principal.”<sup>180</sup>

The District of Columbia also specifies in detail who is not permitted to be a supporter, and does not permit people who provide support services,<sup>181</sup> own or operate an organization that provides services,<sup>182</sup> or works for state agencies that are “financially responsible for the supported person’s care” to be supporters, unless they are relatives.<sup>183</sup> Further, persons who have harmed or exploited the principal or a child, older person, or person with a disability,<sup>184</sup> or who have committed other types of crimes, such as fraud and theft, are not permitted to be supporters.<sup>185</sup>

Texas, Wisconsin, and Indiana do not specify classes of individuals ineligible to be supporters, but circumstances are specified, that if occurring, terminate the agreement.<sup>186</sup>

### 5. *Supporter’s Role and Authority*

Texas expressly designates supporters as fiduciaries,<sup>187</sup> and limits the supporter only to “exercise the authority granted . . . in the supported decision-making agreement.”<sup>188</sup> While the other states do not expressly classify supporters as fiduciaries, Indiana describes the relationship between principals and supporters as “one of trust and confidence,”<sup>189</sup> and Alaska directs supporters to “act with the care, competence, and diligence ordinarily exercised by individuals in similar circumstances.”<sup>190</sup> And in the District of Columbia, legislation confines supporters’ authority to that specified in the agreement.<sup>191</sup>

Delaware also specifically prohibits supporters from:

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179. DEL. CODE ANN. tit. 16, § 9406A(b)(1)–(2); ALASKA STAT. § 13.56.020(1)–(2).

180. DEL. CODE ANN. tit. 16, § 9406A(b)(3). Alaska’s statute is similarly worded. ALASKA STAT. § 13.56.020(3).

181. D.C. CODE § 7-2132(a)(1) (2019).

182. *Id.*

183. *Id.* § 7-2132(a)(2).

184. *Id.* § 7-2132(b)(1)(A)–(b)(1)(B)(ii).

185. *Id.* § 7-2132(b)(1)(B).

186. *See infra* Section III.B.8.

187. TEX. EST. CODE ANN. § 1357.052(b)–(c) (West 2018).

188. *Id.* § 1357.052(a). Wisconsin and D.C. use very similar language. *Compare*, WIS. STAT. ANN. § 52.12 (West 2018); *with* D.C. CODE § 7-2133(b).

189. IND. CODE ANN. § 29-3-14-5(b) (West 2019).

190. ALASKA STAT. § 13.56.090 (2018).

191. D.C. CODE § 7-2133(a)(1)–(3).

(1) Exerting undue influence upon, or making decisions on behalf of, the principal.

(2) Obtaining, without the consent of the principal, information that is not reasonably related to matters with which the supporter is authorized to assist under the supported decision-making agreement.

(3) Using, without the consent of the principal, information acquired for a purpose other than assisting the principal to make a decision under the supported decision-making agreement.<sup>192</sup>

#### 6. *Scope of Agreement*

Legislation also specifies the scope of the supported decision-making agreement.<sup>193</sup> Texas permits a principal to *voluntarily* authorize the supporter to do any or all of the following:

(1) provide supported decision-making, including assistance in understanding the options, responsibilities, and consequences of the adult's life decisions, without making those decisions on behalf of the adult with a disability;

(2) . . . assist the adult in accessing, collecting, and obtaining information that is relevant to a given life decision, including medical, psychological, financial, educational, or treatment records, from any person;

(3) assist the adult with a disability in understanding the information . . . ; and

(4) assist the adult in communicating the adult's decisions to appropriate persons.<sup>194</sup>

The scope of the supported decision-making agreements is similar in the other jurisdictions. Alaska adds that if authorized by the principal, the sup-

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192. DEL. CODE ANN. tit. 16, § 9406A(c)(1)–(3) (2018). Indiana's statute contains similar prohibitions. IND. CODE ANN. § 29-3-14-5. Alaska's statute also contains these prohibitions, with the addition that supporters are not permitted to sign for the principal. ALASKA STAT. § 13.56.110. Wisconsin also prohibits supporters from signing legal documents on behalf of the principal. WIS. STAT. ANN. § 52.10(2).

193. Delaware does not have a scope section in its statute, but the scope of the agreement can be inferred from other parts of the law, including the language on the agreement form and the section on supporters. DEL. CODE ANN. tit. 16, § 9406A(a)(1)–(5). Similarly, Indiana does not have a scope section, but in other parts of the statute, directs supporters to “act within the scope set forth in the . . . agreement” and prohibits supporters from “acting outside the scope of authority provided in the . . . agreement.” IND. CODE ANN. § 29-3-14-5(a)(3)–(c)(4). Alaska likewise does not have a scope section, but does direct what supporters are able to do, except as limited by the terms of the agreement. ALASKA STAT. § 13.56.100(a).

194. TEX. EST. CODE ANN. § 1357.051(1)–(4) (West 2018).

porter can be present when the principal is meeting with others and participate in the discussion and can advocate to “ensure the implementation of the principal’s wishes and decisions.”<sup>195</sup>

Texas, Wisconsin, Delaware, and Indiana specify that even if a person has an agreement with supporters, they can still access information without their supporters.<sup>196</sup>

### 7. *Form of Agreement*

Most statutes either provide the form of the supported decision-making agreement or direct that a state agency create a form.<sup>197</sup> The Texas statute provides the form of the agreement,<sup>198</sup> which can also be found on the website of the Texas Council for Developmental Disabilities.<sup>199</sup> The form is two pages, and the agreement begins with a brief description of its purpose, and then contains a checklist where the principal can mark “yes” or “no” in what areas their supporters may provide assistance in decisionmaking, including: “obtaining food, clothing and a place to live”; “physical health”; “mental health”; “managing . . . money or property”; “getting an education or other training”; “choosing and maintaining . . . services and supports”; “finding a job”; and “Other” with space to specify.<sup>200</sup> The agreement form also has the principal specify whether their supporter can see private health information and educational records.<sup>201</sup> The second page of the agreement directs people presented with the agreement to rely on it, and exempts them from liability as long as they rely on it in good faith.<sup>202</sup> However, at the end of the agreement, there is a bolded and capitalized heading: “WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY.” This section states that if a person presented with the agreement suspects or knows the principal is being exploited or abused by their supporter, they are directed to

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195. ALASKA STAT. § 13.56.100(a)(3).

196. TEX. EST. CODE ANN. § 1357.054(c); WIS. STAT. ANN. § 52.16(5); DEL. CODE ANN. tit. 16, § 9404A(c); IND. CODE ANN. § 29-3-14-4(c).

197. Indiana’s statute has information that must be in the agreement to be presumed to be valid but does not contain a template or direct a state agency to create a form. IND. CODE ANN. §§ 29-3-14-7(a), 29-3-14-10. At the time of this writing, Indiana’s state government website that describes supported decision-making agreements does not contain a sample agreement. *See Supported Decision-Making*, IN.GOV, <https://www.in.gov/gpcpd/2729.htm> (last accessed Nov. 14, 2019); *Supported Decisionmaking*, THE ARC INDIANA, <https://www.arcind.org/future-planning/supported-decision-making/> (last accessed Nov. 14, 2019).

198. TEX. EST. CODE ANN. § 1357.056.

199. SUPPORTED DECISION-MAKING AGREEMENT, <http://www.tcdd.texas.gov/wp-content/uploads/2015/08/Supported-Decision-Making-Agreement-Oct15.pdf> (last accessed Nov. 16, 2019).

200. *Id.*

201. *Id.*

202. *Id.*

contact the Texas Department of Family and Protective Services, and the Department's contact information is on the form.<sup>203</sup>

The Delaware form has much of the same information. But it also includes a bolded and underlined statement that the principal is the legal decisionmaker ("My appointed person(s) does not make decisions for me"), provides space for the principal to write additional information, and contains a section where the principal can specify areas in which they do not want assistance.<sup>204</sup> While there is a directive to third parties to report if they think the principal needs protective services,<sup>205</sup> no contact information for reporting is provided.

While similar to the other states' forms, the Wisconsin form includes "applying for public benefits" and is more specific in identifying supporter's records access, detailing "Medical," "Psychological," "Financial," "Education," "Treatment," and "Other" records.<sup>206</sup> Wisconsin's form also makes it possible for the principal to further customize the supporter's authority by detailing exactly how support will be provided (i.e., the principal can specify whether their supporter will have access to information, help them understand information, or help communicate a decision).<sup>207</sup> There is no information about adult protective services on the form.

The District of Columbia form, like the Delaware form, directs "NOTHING IN THIS DOCUMENT GIVES MY SUPPORTER PERMISSION TO MAKE DECISIONS FOR ME."<sup>208</sup> Like the Wisconsin form, the D.C. form allows the principal to specify exactly how support will be provided, adding a "yes/no" option for the supporter to be present when providing decision-making assistance.<sup>209</sup> The form also requires that the supporter not only agree to this role, but also affirm that they have not "[a]bused, neglected, or exploited" the principal; harmed a child, older person, or person with a disability; or been convicted of certain crimes.<sup>210</sup> The form ends with information about and contact information for adult protective services.<sup>211</sup>

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203. *Id.*

204. SUPPORTED DECISION-MAKING AGREEMENT—DELAWARE CODE TITLE 16, CHAPTER 94A, SECTION 9401A, [https://www.dhss.delaware.gov/dsaapd/files/supported\\_decision\\_making\\_agreement.pdf](https://www.dhss.delaware.gov/dsaapd/files/supported_decision_making_agreement.pdf) (last accessed Nov. 16, 2019).

205. *Id.*

206. SUPPORTED DECISION-MAKING AGREEMENT—2017 WISCONSIN ACT 345—WISCONSIN CHAPTER 52, [http://wi-bpdd.org/wp-content/uploads/2018/05/Sample\\_SDMForm\\_-5212018.pdf](http://wi-bpdd.org/wp-content/uploads/2018/05/Sample_SDMForm_-5212018.pdf) (last accessed Nov. 16, 2019).

207. *Id.*

208. SUPPORTED DECISION-MAKING AGREEMENT—D.C. CODE §§ 7-2131—2134, <http://www.supporteddecisionmaking.org/sites/default/files/DC-SDMA-Instruction-Form.pdf> (last accessed Nov. 16, 2019).

209. *Id.*

210. *Id.*

211. *Id.*

Alaska's statute provides a form but allows for other forms of the agreement that are "substantially similar."<sup>212</sup> Alaska's form, like some states' forms, says "A SUPPORTER APPOINTED UNDER THIS AGREEMENT DOES NOT MAKE DECISIONS FOR ME."<sup>213</sup> The form is six pages in length and contains space to nominate three different supporters and an alternate and specify for each of the nominated supporters exactly what kind of support they can provide.<sup>214</sup> In addition to decision-making domains covered in other states' forms, the Alaska form also includes "[m]aking choices about how I spend my time" and "[m]aking choices about legal matters."<sup>215</sup> The principal can also authorize decision-making support in additional domains (by writing them on the form), and can also specify areas where the principal does not authorize support.<sup>216</sup> The principal also specifies "yes" or "no" about whether the supporters can share information with one another.<sup>217</sup> The form also requires the permission and signature from a guardian, if the principal wishing to enter a supported decision-making agreement is under guardianship, and all supporters must sign the form agreeing to be supporters and declaring that they will fulfill their responsibilities under this law.<sup>218</sup> The fifth section on the agreement, midway through the form, gives a notice to third parties about what supported decisionmaking is and that they should recognize decisions made with support as the principal's decisions.<sup>219</sup> There is no warning to third parties about reporting suspected abuse or neglect.<sup>220</sup> The form also specifies the duration and term of the agreement.<sup>221</sup>

#### 8. *Term of Agreement*

Supported decision-making legislation also specifies when supported decision-making agreements end.<sup>222</sup> Agreements end when terminated by either the principal or the supporter.<sup>223</sup> In Texas, the agreements also end if:

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212. STATUTORY FORM FOR SUPPORTED DECISION-MAKING AGREEMENT, [http://dhss.alaska.gov/gcdse/Documents/projects/SDMA/SDMA\\_FORM.pdf](http://dhss.alaska.gov/gcdse/Documents/projects/SDMA/SDMA_FORM.pdf) (last accessed Nov. 16, 2019); *see also* ALASKA STAT. § 13.56.180 (2018).

213. STATUTORY FORM FOR SUPPORTED DECISION-MAKING AGREEMENT, *supra* note 212.

214. *Id.*

215. *Id.*

216. *Id.*

217. *Id.*

218. *Id.*

219. *Id.*

220. *Id.*

221. *Id.*

222. Alaska also specifies when supported decision-making agreements begin. ALASKA STAT. § 13.56.180 (2018).

223. *Id.* § 13.56.080(a); D.C. CODE § 7-2132(e) (2019); IND. CODE ANN. § 29-3-14-9 (West 2019); TEX. EST. CODE ANN. § 1357.053(a) (West 2018). Wisconsin's law goes into detail about the form of revocation of a supported decision-making agreement. *See* WIS. STAT. ANN. § 52.14(3)(a)–(c) (West 2018).

(1) the Department of Family and Protective Services finds that the adult with a disability has been abused, neglected, or exploited by the supporter;

(2) the supporter is found criminally liable for [certain] conduct . . . ; or

(3) a temporary or permanent guardian of the person or estate appointed for the adult with a disability qualifies.<sup>224</sup>

In Indiana, agreements are terminated if a court finds that the principal did not have the capacity to enter the agreement, appoints a plenary guardian for the principal, or finds that a supporter used the agreement to financially exploit, neglect, or abuse the principal.<sup>225</sup> In Wisconsin, agreements also end for findings of supporter abuse, neglect, and criminal liability, and if the supporter has a restraining order against them.<sup>226</sup> In Delaware, the District of Columbia, and Alaska, agreements would presumably end if a supporter no longer qualified because they met one of the conditions of disqualification discussed previously.<sup>227</sup>

#### 9. *Reliance on Agreement and Limitations of Liability*

The Texas, Wisconsin, and District of Columbia supported decision-making statutes instruct people who are given a copy of the supported decision-making agreement to rely on it, except if abuse or exploitation is suspected.<sup>228</sup> Indiana directs that “[a] request or decision made or communicated with the assistance of a supporter in conformity with this chapter shall be recognized as the request or decision of the adult for the purposes of any provision of law,”<sup>229</sup> and Alaska’s statute contains similar wording.<sup>230</sup>

In contrast, Delaware’s statute is silent on whether the agreement should be relied upon, but outlines under what conditions people will not be liable if they do not rely on the agreement.<sup>231</sup> In all states, as long as relying or declining to rely on the agreement is reasonable and in good faith, then a third party will not be subject to civil or criminal liability.<sup>232</sup> Some states also

224. TEX. EST. CODE ANN. § 1357.053(b).

225. IND. CODE § 29-3-14-9(4)–(6).

226. WIS. STAT. ANN. § 52.14(2).

227. *See supra* Section III.B.4. In Delaware, agreements also may be terminated upon a judicial determination that the principal cannot make decisions despite assistance. DEL. CODE ANN. tit. 16, § 9405A(i) (2018).

228. TEX. EST. CODE ANN. § 1357.101(a); WIS. STAT. ANN. § 52.30(1); D.C. CODE § 7-2133(d).

229. IND. CODE § 29-3-14-6.

230. ALASKA STAT. § 13.56.130 (2018).

231. DEL. CODE ANN. tit. 16, § 9408A.

232. ALASKA STAT. § 13.56.140(a); DEL. CODE ANN. tit. 16, § 9408A; IND. CODE § 29-3-14-11; TEX. EST. CODE ANN. § 1357.101(b); WIS. STAT. ANN. § 52.30(2). Wisconsin further specifies that *supporters* will not be liable as long as they act with prudence and in good faith. WIS. STAT. ANN. § 52.30(8). Supporters are presumably protected from liability under the general limits to

specify that there will be no professional liability (i.e., finding of unprofessional conduct) for good faith reliance on supported decision-making agreements.<sup>233</sup>

Some of the supported decision-making statutes contain provisions specific to healthcare providers. In Delaware and Alaska, for example, there is a conscience exception for healthcare providers.<sup>234</sup> Alaska also permits healthcare providers to decline to follow their supported patient's wishes if "contrary to [their] good faith medical judgment."<sup>235</sup> Wisconsin outlines extensive limitations of liability for healthcare providers treating principals with a supported decision-making agreement,<sup>236</sup> while also directing that providers are responsible for meeting the standard of care to their patients, acting consistent with the wishes of their patient, and relaying sufficient information for informed consent to be possible.<sup>237</sup>

#### *10. Mandate to Report Suspected Exploitation or Abuse*

Most supported decision-making laws direct persons presented with supported decision-making agreement forms to report any suspected abuse, neglect, or exploitation.<sup>238</sup>

#### *11. Relationship of Supported Decisionmaking to Guardianship*

All states have guardianship laws, and in states where supported decisionmaking is an option, persons with disabilities continue to be placed under

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liability in other states' statutes or if they meet the duty of care directed by statute. *See, e.g.*, DEL. CODE ANN. tit. 16, § 9406A(d) (defining supporter's duty of care).

233. ALASKA STAT. § 13.56.140(a); D.C. CODE § 7-2133(e); IND. CODE § 29-3-14-11(a).

234. DEL. CODE ANN. tit. 16, § 9408A ("A person who in good faith acts in reliance on an authorization in a supported decision-making agreement, or who in good faith declines to honor an authorization in a supported decision-making agreement, is not subject to civil or criminal liability or to discipline for unprofessional conduct for . . . [d]eclining to comply with an authorization related to health care in a supported decision-making agreement because the action proposed to be taken under the agreement is contrary to the conscience or good faith medical judgment of the person or to a written policy of a health-care institution that is based on reasons of conscience."); ALASKA STAT. § 13.56.140(a)(3).

235. ALASKA STAT. § 13.56.140(a)(3).

236. WIS. STAT. ANN. § 52.30(3).

237. *Id.* § 52.30(6). Additionally, healthcare providers must also abide by the ADA and make any necessary accommodations for their patients with disabilities. *Id.* § 52.30(7).

238. D.C. CODE § 7-2133(f); IND. CODE ANN. § 29-3-14-13; TEX. EST. CODE ANN. § 1357.102 (West 2018); WIS. STAT. ANN. § 52.32(1). Delaware's statute does not contain this directive, but its form does. Neither the text of the Alaska statute nor the template form provided online contain this mandate.

guardianship,<sup>239</sup> and, in fact, may not be eligible for supported decisionmaking if they have a guardian.<sup>240</sup> States without supported decision-making laws may include a reference to supported decisionmaking in their guardianship statutes, however.<sup>241</sup> For example, in Maine, guardians can only be appointed if a person with a disability has “a limitation in the ability to receive and evaluate information or make or communicate decisions even with the use of appropriate supportive services, technological assistance and supported decision making.”<sup>242</sup>

Even when supported decisionmaking is not referenced in a state’s statutes, courts may discuss supported decisionmaking when determining whether a guardian will be appointed.<sup>243</sup> For example, a New York court determining whether guardianship continued to be appropriate for a woman with an intellectual disability wrote:

I would find that guardianship is no longer warranted because there is now a system of supported decision making in place that constitutes a less restrictive alternate to the Draconian loss of liberty entailed by a plenary 17–A guardianship. This use of *supported* decision making . . . is also consistent with . . . Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).<sup>244</sup>

Additionally, this court wrote that supported decisionmaking, where possible, may be a constitutional guarantee under the New York State Constitution and that “supported decision making must be explored and exhausted before guardianship can be imposed.”<sup>245</sup> While this court decision does not constitute precedent, it demonstrates the spread of ideas from the CRPD and has been influential in later New York Surrogate Court decisions, which have used this reasoning to deny guardianship applications.<sup>246</sup>

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239. *See, e.g.*, *Guardianship of A.E.*, 552 S.W.3d 873, 889 (Tex. App. 2018) (“Because supported decision-making calls for giving a person assistance in understanding the person’s options but prohibits a supporter from making decisions for the person, the evidence before the probate court established that this alternative is simply not feasible for A.E.”).

240. ALASKA STAT. § 13.56.010(c); IND. CODE ANN. §§ 29-3-14-4(d), 29-3-14-9(6).

241. MO. REV. STAT. § 475.075(13)(4) (2018). Supported decision-making legislation is often part of a state’s guardianship code.

242. ME. REV. STAT. ANN. tit. 18-C, § 5-401 (2017).

243. *See, e.g.*, *Supported Decision-Making*, DISABILITY RIGHTS FLORIDA (Dec. 15, 2016), [http://www.disabilityrightsflorida.org/podcast/story/episode\\_5\\_supported\\_decision\\_making](http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making).

244. *In re Guardianship of Dameris L.*, 56 N.Y.S.2d 848, 853 (N.Y. Sur. Ct. 2012).

245. *Id.* at 856.

246. *See, e.g.*, *In re Guardian for Michelle M.*, 2016 WL 3981204, at \*7 (N.Y. Sur. Ct. July 22, 2016) (“Michelle has an inherent right and ability to make her own choices, with dignity, independence, and support. . . . To allow Michelle to retain the legal right to make personal decisions about her own affairs, while providing her with any necessary assistance to make or communicate those decisions in a supported decision-making framework which she already has in place, is ultimately in her best interest.”).



*C. Applying Supported Decisionmaking to Dementia*

Because supported decisionmaking has only recently been adopted into U.S. law, there is not good research on who uses it or how it is used. But it is possible to speculate on how it could be applied to persons with dementia. Supported decisionmaking for persons with dementia would likely occur as follows. When a person with dementia realized they had cognitive impairments and that their decision-making capacity would decline over time,<sup>247</sup> the individual could opt to find people to formally agree to support them in instances where they need assistance with understanding information, making decisions, or communicating decisions to others. As long as a proposed supporter agreed and met the necessary state requirements, then when called upon by the person with dementia, the supporter would provide any requested decision-making assistance.

In the healthcare context, the patient with dementia would present to their physician or other healthcare providers a copy of the supported decision-making agreement. The agreement would inform providers that the person with dementia is the rightful healthcare decisionmaker and that they have supporters rather than surrogates, and it would also specify what kind of private healthcare information their supporter should have access to. The patient with dementia would then be able to make their own healthcare decisions, with any necessary supports, even if under the typical surrogate decision-making model, they would be determined to not have decisional capacity and a surrogate would decide for them. If the patient later became unable to make or communicate decisions even with support, then surrogates (who may have been the supporter) could decide on the patient's behalf.

#### IV. OTHER CONSIDERATIONS

There may be significant concerns about shifting from surrogate to supported decisionmaking for persons with dementia. Some of these concerns are specific to dementia, and some are about supported decisionmaking generally; some are practical, and some are philosophical. Before changing law and practice, it is important to consider and address these concerns. This Part first focuses on more practical concerns, such as how supported decisionmaking can best be applied to persons with dementia. This Part then addresses more philosophical issues with dementia and decisionmaking, such as changes to personal identity after the onset of dementia.

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247. This would likely occur at the time of a dementia diagnosis. A person with dementia could opt in to supported decisionmaking at any point in their illness, however, even if they previously relied on surrogates or agents.

*A. Supported Decisionmaking Is Appropriate for Many but Not All Persons with Dementia*

This Section addresses concerns that supported decisionmaking is not possible for persons with dementia given the nature of this disability. While this Article contends that supported decisionmaking can work for many persons with dementia, depending upon the stage of the illness and the preferences of particular patients, this model will not always be appropriate.

*1. Supported Decisionmaking Can Be Useful for Many Persons with Dementia*

There is debate in the scholarly and policy literature about whether supported decisionmaking is appropriate or even possible for persons with dementia. For example, questions arise about whether a decision-making model that arose in the context of “the needs of young adults with developmental and intellectual disabilities”<sup>248</sup> will work for persons with dementia.<sup>249</sup>

It is crucial to emphasize that supported decisionmaking may not be welcome for all persons with MCI or dementia.<sup>250</sup> For persons with only mild decisional impairments, there is no legal or clinical need for anyone to be involved in a healthcare decision besides the patient and their physician (although such persons may invite others into the process, if this is their decision-making preference).<sup>251</sup> Indeed, it is important to underscore that this

248. Hall, *supra* note 81, at 346.

249. As others have noted, the experiences and abilities of persons who have cognitive disabilities differ greatly. Mary Donnelly, *A Legal Overview*, in *THE LAW AND ETHICS OF DEMENTIA*, *supra* note 11, at 271, 272; Kohn et al., *supra* note 13, at 1132, 1133. Additionally, it is likely that the experience of supported decisionmaking will differ for persons who were previously able to make their own decisions (e.g., older persons with dementia) and those who are able to make their own decisions for the first time (e.g., persons with Down Syndrome who attain the age of majority). Diller, *supra* note 11, at 525.

250. See *infra* Section IV.A.2.

251. Medical organizations acknowledge that persons with early-stage dementia may be fully capable of making their own decisions. WORLD HEALTH ORG., *supra* note 27, at 45. Clinical practice may need to change to ensure surrogates are not necessary, however. For example, a clinician may need to slow down when talking to patients with dementia. Or appointments may need to be scheduled for when a patient with dementia tends to experience fewer impairments, which may mean conversations should occur in the morning. Nina Khachiyants et al., *Sundown Syndrome in Persons with Dementia: An Update*, 8 PSYCHIATRY INVESTIGATION 275 (2011); see also CASTLEMAN ET AL., *supra* note 31, at 245–46 (providing advice for communicating with a person with dementia); GLENNER ET AL., *supra* note 84, at 39–41; Cheryl Dellasega et al., *Medical Decision-Making Capacity in Elderly Hospitalized Patients*, 2 J. ETHICS L. & AGING 65 (1996) (describing how to accommodate older adults in medical crisis by altering communication style to ensure understanding); J.B. Orange & Ellen Bouchard Ryan, *Alzheimer’s Disease and Other Dementias: Implications for Physician Communication*, 16 CLINICS GERIATRIC MED. 153 (2000); J. Perry et al., *Nurse-Patient Communication in Dementia: Improving the Odds*, 31 J. GERONTOLOGICAL NURSING 43 (2005); Megan S. Wright, *Dementia, Healthcare Decision Making, and Disability*

Article does not argue for abolishing existing healthcare decision-making laws. Instead, this Article argues that existing laws be properly applied to ensure that autonomy is respected. Existing law only permits surrogate decisionmaking when someone is adjudicated incompetent, is found to lack decision-making capacity after an assessment, or intentionally and voluntarily defers to others in decisionmaking.<sup>252</sup> This means that persons who have been diagnosed with MCI or who have early stage dementia where decisional impairments are likely mild should not be prevented from making their own healthcare decisions because they most likely retain decision-making capacity, under clinical criteria, and do not have a guardian.<sup>253</sup> For example, even if a person can no longer easily do arithmetic calculations or periodically experiences confusion, common symptoms of mild AD, they likely can still communicate preferences and make choices about medical treatment. As the World Health Organization noted, “the presence of dementia should not be justification for assuming a person cannot make decisions in all aspects of his/her life.”<sup>254</sup>

Unfortunately, persons with dementia are often denied the opportunity to make their own decisions, even when entitled to under current healthcare decision-making law.<sup>255</sup> To ensure that persons with MCI or mild dementia are protected against clinicians or family members who may find it inconvenient to allow them to participate in decisionmaking<sup>256</sup> or who may misunderstand healthcare decision-making law,<sup>257</sup> persons with dementia should enter into supported decision-making agreements, which proclaim their legal decision-making capacity, upon diagnosis of MCI or dementia. The agreements, which direct physicians to follow them, can be used as a shield against marginalization and a sword of empowerment as persons with dementia demand the legal right to make or participate in healthcare decisions. That is, supported decisionmaking, even when a person has decisional capacity under current capacity assessment criteria, can be a prophylactic measure to ensure that persons with dementia retain autonomy in healthcare settings.<sup>258</sup>

Given the functional impairments dementia causes, however, as dementia progresses many persons may need assistance in making decisions based

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Law, 47 J.L. MED. & ETHICS 25, 29 (2019) (describing accommodations to healthcare decisionmaking for persons with disabilities).

252. See UHCDA, *supra* note 2.

253. Moye et al., *supra* note 139.

254. WORLD HEALTH ORG., *supra* note 27, at 45.

255. See *supra* Section I.C.

256. Charlie Murphy, *The Experience of People with Dementia in Community Services*, in THE PERSON WITH ALZHEIMER'S DISEASE, *supra* note 10, at 187, 207 (“Often it can seem more convenient for the staff to assume that individuals with dementia have little or no insight.”).

257. Miller et al., *supra* note 8, at 1148.

258. The presence of the agreement should be sufficient to ensure that persons who do not want anyone else involved in their healthcare decisionmaking can assert their legal capacity. The use of supporters is always optional.

on their interests and preferences.<sup>259</sup> While some scholars have summarily dismissed supported decisionmaking for persons with dementia,<sup>260</sup> it is important to remember that dementia is a syndrome, and there is significant variation in the experience of persons with dementia.<sup>261</sup> The symptoms of dementia will differ by type and stage, and its impacts will differ depending upon a person's psychological attributes and social context, meaning that it is likely supported decisionmaking would be both appropriate and possible for some persons with dementia. And indeed, studies have demonstrated that persons with dementia can reliably convey their preferences, values, and experiences, which would make supported decisionmaking possible.<sup>262</sup> There is thus no reason to automatically presume that a typical person with moderate AD, for example, would be unable to be supported in healthcare decisionmaking.<sup>263</sup> Even if cognitive impairments are more severe, if a person had high levels of cognitive resources prior to the onset of dementia, adequate support may be sufficient to aid in decisionmaking.<sup>264</sup>

Additionally, informal supported decisionmaking is a process to which most people are already accustomed, and so this model may not require adjustment for persons with dementia, in contrast to surrogate decisionmaking. As noted previously, research has demonstrated that, in practice, many people make important decisions—especially about their healthcare—in consultation and collaboration with others.<sup>265</sup> Consulting and collaborating with other people in decisionmaking is exactly what supported decisionmaking is, albeit in a much more formalized manner given the use of a legal contract.

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259. Miller et al., *supra* note 8, at 645. Needing assistance to decide on the basis of contemporaneous values and interests is not incompatible with autonomy, however. Jaworska, *supra* note 4, at 126.

260. One scholar wrote, “Co or supported decision-making models . . . are not compatible with the embodied nature of dementia.” Hall, *supra* note 81, at 346.

261. KITWOOD, *supra* note 43, at 84–85.

262. Miller et al., *supra* note 8, at 1143, 1151–53; *see also* POWELL, *supra* note 4, at 16 (relaying an anecdote that could be considered informal supported decisionmaking for a person with severe dementia).

263. A person with moderate dementia may need help with activities of daily living, such as toileting and getting dressed, and may exhibit greater confusion and memory loss, but with assistance from trusted supporters, may be able to talk about their healthcare preferences, understand their medical options, and convey their choices. Using supported decisionmaking would require that the person with dementia not be inappropriately sedated, however. Fox et al., *supra* note 11, at 74–75, 78–81.

264. It is beyond the scope of this Article to detail the exact process of how healthcare decisions in a clinical setting would be made with support. There is too much variation in the experience of dementia, and too many kinds of healthcare choices, to tackle this. But for an example of informal supported decisionmaking for a person with advanced dementia, *see*, POWELL, *supra* note 4, at 16; *see also* *Using Supported Decision Making in Health Care: Frequently Asked Questions for Persons with Disabilities, Family Members, Friends, and Supporters*, NAT'L DISABILITY RTS. NETWORK, <https://www.ndrn.org/resource/faqs-for-people-with-disabilities-and-their-family-members-supported-decision-making-and-health-care/> (last visited Dec. 19, 2019) (listing examples of how support can be provided in healthcare setting).

265. Wright, *supra* note 20.

Supported decisionmaking thus facilitates the continuation of a familiar mode of decisionmaking even after the onset of a condition that impairs cognition. If used in the context of dementia, supported decisionmaking may increase the likelihood that persons with dementia are treated the same as persons without dementia.

*2. Surrogate Decision-making and Guardianship Laws Should be Retained and Include Supported Decision-making Principles*

Despite the desire of some advocates for persons with disabilities to abolish surrogate decisionmaking,<sup>266</sup> this decision-making model is sometimes appropriate and necessary.<sup>267</sup> In the case of dementia, there may come a point in this degenerative disorder when a person becomes nonverbal.<sup>268</sup> Not being able to speak is not a bar to using supported decisionmaking, however, if the person with dementia can still gesture or otherwise behaviorally manifest desires, preferences, and choices.<sup>269</sup> But for some persons, dementia will progress to the point where it is not possible for them to communicate.<sup>270</sup> When communicative abilities are completely lost or uninterpretable in late stage dementia, supported decisionmaking will not be possible, and a surrogate will be required, whether the surrogate is a family member or a guardian appointed by a court.<sup>271</sup> But if a surrogate was previously a supporter, they likely have a good sense of how best to make decisions on the basis of the values and preferences of the person with dementia.<sup>272</sup>

Also, some persons with dementia may not have anyone in their lives who can serve as a supporter. This may be because they have no family or friends,<sup>273</sup> or because potential supporters are disqualified under state law (for example, they have abused or neglected the person with dementia) or are otherwise unwilling or unable to be a supporter (perhaps they too have a cognitive disability). In these instances, guardians may still need to be appointed.<sup>274</sup>

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266. ARSTEIN-KERSLAKE, *supra* note 154, at 74.

267. For example, if a person is unconscious, no amount of support will aid them in decisionmaking.

268. Diller, *supra* note 11, at 533–34 (describing how not all persons with dementia can be supported); Snyder, *supra* note 91, at 129 (“[A]s the disease advances communication . . . may become more symbolic or may shift from verbal to more behavioral or gestures.”).

269. See Kathleen Kahn-Denis, *The Person with Dementia and Artwork: Art Therapy*, in *THE PERSON WITH ALZHEIMER’S DISEASE*, *supra* note 10, at 246 (describing how persons with dementia can use art to express themselves and relate to others).

270. Herring, *supra* note 129, at 303. They may also no longer have preferences or any awareness at all. In other cases, a person may die from other causes before dementia reaches this stage.

271. Schmidt, *supra* note 70, at 321.

272. WORLD HEALTH ORG., *supra* note 27, at 45.

273. See Diller, *supra* note 11, at 522 (describing social isolation of older persons).

274. Some have argued for professionalizing support for instances such as this, however. Stephen A. Rosenbaum, 39 J. LEGAL MED. 61 (2019) (reviewing ANNA ARSTEIN-KERSLAKE,

Because surrogate decisionmaking will sometimes be necessary, laws facilitating surrogate decisionmaking are also necessary. Additionally, these laws should be retained because people should be able to voluntarily opt out of decisionmaking if they prefer others to decide for them, as this choice is also an exercise of autonomy the law should respect. Indeed, some studies have found that older patients may have this preference.<sup>275</sup> Because some persons with dementia who are able to make their own decisions, with or without support, may prefer to defer to others, supported decisionmaking should be optional rather than mandatory.<sup>276</sup>

Given the need to retain surrogate decision-making and guardianship law and the importance of self-determination to persons with dementia, principles of supported decisionmaking should be built into these laws. That is, where possible, surrogates and guardians should support persons with disabilities in making their own decisions rather than taking over the decision-making process.<sup>277</sup> For example, while a guardian may be the legal decisionmaker, the guardian could inform the person with dementia about possible medical options along with the expected benefits and burdens, obtain feedback from the person with dementia about their preferences, and try to decide on the basis of these preferences, even if the guardian legally could decide otherwise.

### *B. Supported Decisionmaking Should Be Institutionalized in Law*

A large-scale shift from surrogate to supported decisionmaking will require significant institutional and cultural change and may be costly. This Section addresses these concerns and argues that supported decisionmaking for patients with dementia should still be adopted into law.

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RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES: REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW (2017)).

275. Sinoff & Blaja-Lisnic, *supra* note 61, at 98. This means surrogate decision-making laws are needed to facilitate satisfaction of this preference.

276. This is also culturally competent as people from some cultural groups may prefer others (e.g., family members or physicians) to make healthcare decisions on their behalf. INST. OF MED., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE 150 (2015).

277. Guardians are directed to do so in the most recent version of the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act. UGCOPPA, *supra* note 80, at § 313(b)(2).

States should modify their existing healthcare decision-making laws to privilege supported decisionmaking before surrogates are asked to decide on the basis of prior wishes, substituted judgments, or best interests of persons with impaired cognition. This direction would function similarly to how supported decisionmaking is referenced in some state's guardianship statutes. *See supra* Section III.B.11.

1. *How to Institutionalize Supported Decisionmaking for Patients with Dementia*

Supported decisionmaking is codified in the laws of only a few states. Advocates should push for more states to adopt supported decision-making legislation or at least amend their healthcare decision-making statutes to include a mandate to explore supported decisionmaking before turning to a surrogate.<sup>278</sup> Even if other states adopt supported decisionmaking, however, there is no guarantee that this decision-making model would be widely used by persons with dementia.<sup>279</sup> There is also no guarantee that other parties would respect the supported decision-making agreements.<sup>280</sup>

The training and practice of various professionals will need to change in order for supported, rather than surrogate, decisionmaking to be institutionalized in the United States. Elder law, estate, and disability attorneys who help their clients plan for loss of capacity should be aware that supported decisionmaking is a complement to durable power of attorneys, healthcare agents, and living wills. Elder law and estate attorneys should fold discussion of supported decisionmaking into the services they provide their clients. If the attorney has an ongoing relationship with their client, conversations about supported decisionmaking should occur well before the onset of any disability that impairs cognition in order to normalize this option and help people think carefully about who in their social network they trust to assist in decisionmaking. And if a client seeks guidance for the first time shortly after a diagnosis of dementia, the attorney should educate their client on supported decisionmaking, given that most people will likely not have a prior understanding of this model, and thus may not know to ask about it.

The standardized power of attorney and living will forms provided by states should also be modified to include a supported decision-making agreement. People who plan for a future where they may have a disability, but who do not have an attorney, may search for these forms online, and if the supported decision-making agreement is part of the form, then more people will be aware of and use this model.

Probate judges also should undergo training about supported decisionmaking as these judges are responsible for deeming a person incompetent and appointing guardians and conservators. Given that some states have

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278. It is preferable to have separate legislation, however, because extensive directions, grants of authority, and limitations of liability can be outlined.

279. Even in states that have supported decision-making laws, lawyers and healthcare providers may not realize that persons with dementia can benefit from them.

280. Indeed, there is evidence that even legal changes that are meant to promote greater participation in decisionmaking by persons with cognitive disabilities may not change decision-making practices, even by legal actors. Donnelly, *supra* note 249, at 276. Additionally, there is evidence that healthcare providers do not respect existing legal documents, such as advance directives. Davis, *supra* note 4, at 745.

amended their guardianship laws to emphasize that least restrictive alternatives, including supported decisionmaking, should be explored prior to appointing a guardian,<sup>281</sup> judges should be familiar with how supported decisionmaking works so that guardians are not appointed for people who have the ability to make decisions with adequate support and accommodations.

A more significant issue is whether legal change will change clinical practice, which is not overseen by courts.<sup>282</sup> Healthcare providers will also need to be informed and trained about supported decisionmaking. Physicians and other providers diagnose dementia and (if following best practices) then advise their patients to engage in advance care planning.<sup>283</sup> The point of diagnosis and recommendation to plan for loss of capacity is a prime opportunity to inform patients about supported decisionmaking, perhaps by making a medical social worker available to explain how it compares to surrogate decisionmaking. Without an understanding of how other legal tools, such as a supported decision-making agreement, can ensure that patients with decisional impairments are able to make their own healthcare decisions, healthcare providers may be the first actors who treat the person with dementia as *demented and thus incapable*, interacting with the patient only through the patient's family members upon diagnosis.<sup>284</sup> Clinicians should be trained to talk directly to their patients with dementia and expect that they, rather than a family member, are the proper decisionmaker.<sup>285</sup>

Understanding supported decisionmaking and acknowledging that their patient is the rightful healthcare decisionmaker may make healthcare providers more likely to provide respectful, person-centered care to their patients with dementia. And given the rise in academic writing that asserts that shared decisionmaking, which shares similarities with supported decisionmaking, is a best clinical practice, healthcare providers may be more open to supported decisionmaking.<sup>286</sup> But there is also the possibility that clinicians may

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281. See, e.g., N.D. CENT. CODE § 30.1-28-04 (2017).

282. Donnelly, *supra* note 249, at 277 (“[D]elivery on the legal standard is largely dependent on the people who are providing care on the ground.”).

283. There is inconsistency in messaging to clinicians about what information they should give to and how they should interact with their patients with dementia. On the one hand, advance care planning is recommended, which emphasizes precedent autonomy. See, e.g., Bregnan & Moore, *supra* note 92; Fox et al., *supra* note 11. On the other hand, clinicians are advised to recognize the agency and independence of their patients, which emphasizes current interests. Bregnan & Moore, *supra* note 92; Fox et al., *supra* note 11, at 75.

284. See BEARD, *supra* note 18; Young, *supra* note 10, at 39–40 (finding that patients with AD report their healthcare providers do not communicate with them directly).

285. This is consistent with the nondiscrimination mandate in the Americans with Disabilities Act. See *infra* Section IV.B.2.

286. But efforts to get physicians to engage in shared decisionmaking have not been successful, which is not promising news for trying to change how physicians interact with their patients. INST. OF MED., *supra* note 276, at 351. Supported decisionmaking would have the force of law, however, so perhaps its implementation would be more successful. It also may be beneficial to focus education efforts on medical students if the existing medical culture is resistant to viewing patients with



choose not to respect patient choices,<sup>287</sup> which is a more difficult problem to tackle. Supported decisionmaking may be a partial solution to this problem, however, because strong supporters can insist that clinicians respect the principal.

Through advocacy efforts, large and influential organizations such as the Alzheimer's Association or AARP may also provide the necessary impetus for cultural, professional practice, and legal change.<sup>288</sup> But such organizations must be convinced that supported decisionmaking is good for their membership.<sup>289</sup> To this end, a public relations campaign emphasizing that persons with dementia retain significant abilities despite their impairments may be useful.<sup>290</sup>

## 2. *Supported Decisionmaking Should Be Implemented Even If It Adds Administrative Burdens*

Some skeptics of the feasibility of supported decisionmaking may be concerned that healthcare providers will not be receptive to this model because it could be administratively burdensome. Dementia can cause communication issues, including "problems with aphasia, word finding, and sentence completion."<sup>291</sup> Supported decisionmaking may therefore require more time to accommodate a patient's disability,<sup>292</sup> and it may be more efficient for providers to communicate only with surrogates. Prior research has demonstrated that "[w]ell-intentioned caregivers often 'take over' tasks from [people with dementia], especially when the individual is struggling or frustrated by a task."<sup>293</sup> There may be a similar tendency from supporters and

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dementia as capable of making their own healthcare decisions. Medical practice may then change for future generations of physicians.

287. Schmidt, *supra* note 70, at 313 (describing studies that demonstrate that patient instructions are not followed).

288. Additionally, books targeted toward family members and informal caregivers of persons with dementia could also discuss supported decisionmaking as a complement to other types of advance care planning commonly advised. See, e.g., CASTLEMAN ET AL., *supra* note 31, at 105–06, 274–75.

289. See Diller, *supra* note 11, at 498–99 (describing the need for stakeholder buy-in).

290. WORLD HEALTH ORG., *supra* note 27.

291. Robyn Yale & Lisa Snyder, *The Experience of Support Groups for Persons with Early-Stage Alzheimer's Disease and Their Families*, in THE PERSON WITH ALZHEIMER'S DISEASE, *supra* note 10, at 228, 239.

292. See Arwen H. Pieterse et al., *Shared Decision Making and the Importance of Time*, 322 J. AM. MED. ASS'N 25 (2019) (describing how a barrier to adoption of a similar decision-making model is lack of time).

293. Rebecca G. Logsdon, *Making the Most of Every Day: Quality of Life*, in THE PERSON WITH ALZHEIMER'S DISEASE, *supra* note 10, at 75, 83.

healthcare providers to “take over” rather than support a person with dementia in making a healthcare decision.<sup>294</sup>

But what is most convenient for providers should not determine whether supported decisionmaking is used in a healthcare setting. The decisive question is to what are patients with dementia entitled, and the answer is the opportunity to make their own healthcare decisions.<sup>295</sup> There are both legal and ethical sources for this right. For example, if correctly applied, existing healthcare decision-making law entitles persons with dementia who still have decisional capacity to make their own healthcare decisions. Additionally, under the ADA, which requires reasonable accommodations to ensure that persons with disabilities can participate in decisions about their healthcare,<sup>296</sup> persons with dementia may be legally entitled to appropriate decision-making assistance and accommodations.<sup>297</sup> And ethical principles such as equal respect for persons under the law and respect for patient autonomy and self-determination similarly support the proposition that persons with dementia should not be prevented from making their own healthcare decisions.<sup>298</sup>

If there is concern that law is insufficient to ensure that physicians respect the decision-making authority of their patients with dementia, policy-makers may consider monetary incentives to change physician behavior. For example, there could be changes to Medicare to allow healthcare providers to bill for additional time spent accommodating supported decisionmaking.<sup>299</sup> Additionally, other clinicians, such as nurse practitioners, physician

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294. Experts thus advise that when talking to someone with dementia, people should “avoid run-on sentences or raising many questions and points all at once. Allow silence or extra time for participants to find their words.” Yale & Snyder, *supra* note 291, at 239. For other advice for communicating with persons with dementia, see CASTLEMAN ET AL., *supra* note 31, at 39–41; GLENNER ET AL., *supra* note 84, at 39–41; Dellasega et al., *supra* note 251; Orange & Ryan, *supra* note 251; Perry et al., *supra* note 251. **Error! Bookmark not defined.**

295. Clinicians may argue that there are some medical situations in which there is not time to use supported decisionmaking because a decision must be made immediately. While this may be the case in some situations, it is important not to let this rarity become routine justification for denying persons with disabilities the opportunity to make their own healthcare decisions.

296. See, e.g., Megan S. Wright & Joseph J. Fins, *Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience*, 16 YALE J. HEALTH POL’Y L. & ETHICS 233 (2016). But see Nicole D. Agaronnik et al., *Knowledge of Practicing Physicians About Their Legal Obligations when Caring for Patients with Disability*, 38 HEALTH AFF. 545, 547–50 (2019) (finding that physicians are ignorant of their obligations under the ADA).

297. Wright, *supra* note 251. **Error! Bookmark not defined.**, at 28–29.

298. See *supra* Section II.A.

299. But see Megan S. Wright, *Change Without Change? Assessing Medicare Reimbursement for Advance Care Planning*, 48 HASTINGS CTR. REP., May–June 2018, at 8 (showing little effect of reimbursement on physicians billing for advance care planning). Ideas about how to pay for collaborative dementia care are currently being debated. See, e.g., Malaz Boustani et al., *An Alternative Payment Model to Support Widespread Use of Collaborative Dementia Care Models*, 38 HEALTH AFF., Jan. 2019, at 54.

assistants, and social workers, may be able to take on some of the communication with persons with dementia and their supporters.

### 3. *Formality of Law Is Necessary*

One objection to the argument that persons with dementia should be encouraged to enter formal supported decision-making agreements is that doing so signals a lack of respect for rights-bearing adults with mild dementia who are entitled to make their own healthcare decisions under current law. Some may argue that supported decisionmaking should be more informal and relied upon only when necessary (i.e., the person lacks decisional capacity but can still communicate preferences).

It is worth emphasizing again that persons with MCI and mild dementia, who still retain significant cognitive abilities, are entitled to make their own decisions under current healthcare decision-making law, which is premised on decisional capacity.<sup>300</sup> But, as noted previously, these individuals' capacity is often disregarded, and they are excluded by physicians and family members from the decision-making process.<sup>301</sup> Supported decisionmaking can be a legal tool that counters the marginalization of persons with dementia. Further, encouraging the routine practice of supported decisionmaking is a worthy ideal even for persons without cognitive impairments, as it matches relational healthcare decision-making preferences.<sup>302</sup>

Additionally, for persons with moderate dementia, who under existing healthcare decision-making law are not entitled to make their own decisions at the time they must be made because they lack decisional capacity, physicians may be uncomfortable with supported decisionmaking if this model is not found in law. This discomfort may be because physicians fear liability if they permit a patient with moderate dementia to make their own healthcare decisions that ultimately lead to a decline in health or death.<sup>303</sup> Supported decision-making legislation includes limits to liability for reasonable and good faith reliance on supported decision-making agreements.<sup>304</sup> To increase the likelihood of physician buy-in, supported decisionmaking should be formalized in law, with the accompanying limits to liability.

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300. See UHCDA, *supra* note 2.

301. See *supra* Section I.C.

302. Indeed, supported decisionmaking shares similarities with shared decisionmaking, which is preferred by many patients. Kohn et al., *supra* note 13, 1146–48; Wright, *supra* note 20, at 1089.

303. See also Behrens, *supra* note 108 (finding that healthcare providers privilege patient safety over honoring patient preferences because of liability concerns).

Providers also may be concerned about relying on a supported decision-making agreement if it conflicts with the wishes of their patient prior to dementia. See, e.g., Schmidt, *supra* note 70, at 313 (describing sanctions for wrongful life lawsuits and other tort, contract, and criminal claims).

304. See *supra* Section II.B.9.

*C. Addressing Concerns About Financial Exploitation, Undue Influence, and Coercion*

While exploitation and abuse of older persons and persons with disabilities is a general concern,<sup>305</sup> there may be reasons to suppose that persons with dementia are especially vulnerable to financial exploitation.<sup>306</sup> This is because they may have accumulated significant financial assets over their life course, in contrast to many people who have developmental or intellectual disabilities starting at a young age. Financial assets along with impaired cognition may make persons with dementia a target for exploitation, and the progressive nature of dementia means that the risk of exploitation will increase over time.

Importantly, such exploitation may not be directly related to financial decisions, but could also occur in the healthcare decision-making process, given that medical treatment has financial implications. As elder law attorneys caution, “[i]t is almost inevitable that the medical interests of the individual with disabilities and the financial interests of the heirs will conflict because the more money spent on caretaking, the less there will be to inherit.”<sup>307</sup>

Supported decision-making agreements could be used as a means of financial exploitation.<sup>308</sup> This should only occur if persons presented with it are not familiar with supported decisionmaking, and understand the agreement to be a power of attorney, deferring to the supporter who is incorrectly viewed as an agent.<sup>309</sup> It is important to understand, however, that this risk of exploitation and undue influence is not unique to supported decisionmaking. Existing legal tools, such as a power of attorney and guardianship, may make it easier to financially exploit someone.<sup>310</sup> In fact, of all the decision-making options that involve another party, supported decisionmaking may do the most to reduce the risk of exploitation because the person with a disability remains the final decisionmaker (assuming the details of the agreement are followed).<sup>311</sup>

Beyond the context of financial exploitation, other concerns about the exploitation of persons with disabilities arise. Supporters may exert undue

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305. Marshall B. Kapp, *Aging Population*, in THE OXFORD HANDBOOK OF U.S. HEALTH LAW, *supra* note 59, at 1053, 1064–65.

306. See KENNY, *supra* note 36, at 51–54; Arias, *supra* note 81, at 156–57 (recommending financial guardianship).

307. PECK & LAW, *supra* note 12, at 237–38; Wright, *supra* note 20, at 1129.

308. Diller, *supra* note 11, at 535–37.

309. Kohn et al., *supra* note 13, at 1137.

310. PECK & LAW, *supra* note 12, at 286; Schmidt, *supra* note 70, at 313–14.

311. But see Kohn et al., *supra* note 13, at 1137 (arguing that supported decisionmaking has “less accountability” than guardianship given that the agreement and decision-making context are private).

influence, coerce persons with decisional impairments,<sup>312</sup> or even engage in abuse, all of which violate the purpose of supported decisionmaking, which is promoting the self-determination of the principal. As scholars have cautioned, “there is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights.”<sup>313</sup>

It is necessary to acknowledge that the interests of the person with dementia and their supporter may conflict,<sup>314</sup> especially if the supporter is also an informal caregiver. It may be difficult for caregiving supporters to respect the choices of the person with dementia if these choices could result in a decrease in wellbeing.<sup>315</sup> It may also be difficult for supporters to respect choices that increase burdens on themselves in their caregiving capacity.<sup>316</sup>

If supporters are family members, however, the person with dementia may not mind taking into account their supporter’s interests, because the interests of all parties often are considered in family relationships.<sup>317</sup> Furthermore, some argue that the interests of caregivers *should* be considered when making decisions with or for a person with dementia.<sup>318</sup> If in providing supported decisionmaking, the caregiving supporter discusses the impact of a decision on themselves or others, the principal may wish to decide, in part, on the basis of this information, just as they may choose to do if they did not have impaired decision-making capacity.<sup>319</sup> As Professor Herring has noted,

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312. Undue influence is not always a product of bad faith. *Id.* (“Through particular issue-framing, inaccurate assessment of the principal’s preferences, or simple conversational style, a discussion may easily be led one way or another to an outcome that does not accurately reflect the principal’s preferences.”); see also Liz Blackler, *Compromised Autonomy: When Families Pressure Patients to Change Their Wishes*, 18 J. HOSPICE & PALLIATIVE NURSING 284, 284 (2016) (describing family pressure).

313. Kohn et al., *supra* note 13, at 1157.

314. Karen Eltis, *The Use of New Technologies in the Management of Dementia Patients*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 433, 434–35 (“[A]lthough it is naturally presumed that patients and caregivers share common interests, that is not always the case . . .”).

315. *Id.* at 437 (“[C]aregivers . . . are generally said to value non-maleficence over what are perceived to be more abstract rights. That perception might overshadow the dementia patient’s nonmedical considerations . . . that may be conveniently dismissed as capricious or unimportant compared with physical safety . . .”).

316. Empirical studies have demonstrated that there can be significant strain as a result of caring for a person with dementia. Rosie Harding, *Dementia and Carers: Relationality and Informal Carers’ Experiences*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 379, 387; see POWELL, *supra* note 4, at 198–99 (questioning how to balance the needs of caregivers and persons with dementia).

317. See Wright, *supra* note 20 (discussing this in the end-of-life decision-making context).

318. Harding, *supra* note 316, at 389; see Dresser, *Life, Death, and Incompetent Patients*, *supra* note 3, at 395–97 (describing how best interests analyses often do account for family interests); Herring, *supra* note 129, at 306 (arguing that best interests analyses should also be relational).

319. Families may be concerned about permitting their loved ones with dementia to make their own decisions because the decisions could negatively affect family members. But while healthcare decisions may impact others, they are properly made by the person who bears the primary burdens

“[f]ew people would be happy with the idea that if they were to fall incompetent, a decision would have to be made if it benefitted them a little bit, even if that caused grave harm to the person caring for them.”<sup>320</sup> Indeed, persons with dementia may wish to act altruistically.<sup>321</sup>

But given the potential for supported decision-making agreements and practices to result in financial or other harm to persons with dementia, considering how to prevent exploitation, coercion, and abuse is necessary.<sup>322</sup> The focus should not be on limiting the liberty of persons with dementia, but instead on limiting the likelihood that others will harm the person with dementia.<sup>323</sup>

There are existing safeguards in supported decision-making law in the United States that may be helpful for reducing the likelihood of harm to the principal.<sup>324</sup> For example, under some current state laws, certain people are prohibited from serving as supporters, such as those who have an order of protection against them or have abused or neglected the principal in the past.<sup>325</sup> Additionally, most supported decision-making agreements also have a section addressed to third parties that directs those who suspect abuse, neglect, or exploitation of the principal to contact state protective services.<sup>326</sup> Protective services agencies are thus a good complement to supported decisionmaking, given concerns about the wellbeing of persons with dementia.

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and benefits of the decision (the patient). Supported decisionmaking could assuage some family’s concerns about effects of decisions on third parties, however, because while this model permits the person with dementia to make their own decisions, the information a supporter can provide about the potential effects of the decision on others allows the person with dementia to determine which third parties’ interests are relevant for their decision.

320. Herring, *supra* note 129, at 306; *see also* HERRING, *supra* note 72, at 13 (“Clearly people do value their relationships greatly and do not see life as simply about pursuing one’s own goals.”); Wright, *supra* note 20.

321. HERRING, *supra* note 72, at 48–49; Herring, *supra* note 129, at 307. Indeed, there are many studies documenting the altruism of people with dementia. *See, e.g.*, Phyllis Braudy Harris & Casey Durkin, *Building Resilience Through Coping and Adapting*, in *THE PERSON WITH ALZHEIMER’S DISEASE*, *supra* note 10, at 165; Murphy, *supra* note 256; Jane Stansell, *Volunteerism: Contributions by Persons with Alzheimer’s Disease*, in *THE PERSON WITH ALZHEIMER’S DISEASE*, *supra* note 10, at 211.

322. WORLD HEALTH ORG., *supra* note 27, at 45.

323. Martha Albertson Fineman, “Elderly” as Vulnerable: *Rethinking the Nature of Individual and Societal Responsibility*, 20 *ELDER L.J.* 71, 94 (2012).

324. It is important to acknowledge that some persons with disabilities do not trust the legal system to value their lives and so are not assuaged by the existence of legal and procedural safeguards. Jerome E. Bickenbach, *Disability and Life-Ending Decisions*, in *PHYSICIAN-ASSISTED SUICIDE: EXPANDING THE DEBATE* 123 (Margaret P. Battin et al. eds. 1998); Crossley, *supra* note 151, at 909–10.

325. *See supra* Section III.B.4.

326. *See supra* Section III.B.10. All states have elder abuse laws, and some scholars have questioned whether such laws reinforce stigma against older persons. KAPP, *supra* note 73, at 165–69; Kapp, *supra* note 305. But these laws are integral to supported decision-making legislation. And, a third party does not even have to know of the existence of a supported decision-making agreement to contact protective services if they suspect that the principal is being harmed.

States like Wisconsin, where the supported decision-making agreement form does not contain this warning, should add this information to the form. Revising the form to move the warning to the top may also provide additional protection.

There are other safeguards that could be added to supported decision-making laws to further reduce the likelihood of harm to persons with dementia from supported decision-making agreements and practices. For example, people who agree to be supporters could be mandated to undergo training about their duties to the principal and how best to provide support.<sup>327</sup> Also, some scholars have proposed building in opportunities to seek the dissent of the principal in the supported decision-making process,<sup>328</sup> which could further function as a safeguard. Moreover, principals could be advised to have multiple supporters who could serve to check any abuses or pressure of other supporters.<sup>329</sup>

Additionally, in some jurisdictions with supported decisionmaking, such as different provinces in Canada, supporters are monitored.<sup>330</sup> Just as guardians should be monitored for how they handle the accounts of their wards to ensure that they are not financially exploiting people they are supposed to be protecting,<sup>331</sup> it may be beneficial to likewise monitor supporters. Monitors would “make reasonable efforts to determine whether the [supporter] is complying with their legal duties.”<sup>332</sup> If a supporter is not complying, the monitor could ask a court to order the supporter to comply or to remove the supporter.

In sum, while risk of harm to persons with dementia will not be eliminated entirely, safeguards in supported decision-making legislation may help assuage fears that this decision-making model will result in more harm than surrogate decisionmaking.<sup>333</sup>

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327. Kohn et al., *supra* note 13, at 1144. Current books targeted to caregivers of persons with dementia focus on how to be a good caregiver and surrogate decisionmaker, but could be revised to include content on how to be a good supporter. See CASTLEMAN ET AL., *supra* note 31, at 219–59.

328. Dana Howard & Allison McCarthy, Presentation at 21st Annual Conference of the American Society of Bioethics and Humanities: Supported Decision Making: Nondomination Rather Than Mental Prosthesis (Oct. 26, 2019).

329. KENNY, *supra* note 36, at 54.

330. See MICHAEL BACH & LANA KERZNER, LAW COMM’N OF ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY (2010); Kohn et al., *supra* note 13, at 1144; Salzman, *supra* note 73, at 173 (recommending use of monitors); Shih-Ning Then, *Evolution and Innovation in Guardianship Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 133, 160–62 (2013).

331. PECK & LAW, *supra* note 12, at 290.

332. BACH & KERZNER, *supra* note 330, at 118.

333. The alternative is to deny persons with dementia the ability to make healthcare choices. Some may agree that denying persons with disabilities the freedom to so choose is worth it because their medical wellbeing and life are safeguarded. See, e.g., Bickenbach, *supra* note 324, at 126, 129. But I weigh autonomy more heavily, and assert that the cost of privileging autonomy is sometimes going to be medical wellbeing and life.

*D. Possibility of “Bad” Decisions Does Not Outweigh Benefits of Retaining Legal Capacity*

Another significant concern with shifting from use of surrogates is that allowing persons with dementia to make their own decisions may mean that they decide in a manner inconsistent with what others consider to be their best interests. That is, allowing persons with dementia the freedom to decide may result in a “bad” decision.<sup>334</sup>

Indeed, experts have identified the tension between “safety and freedom” as a significant ethical concern for persons with dementia,<sup>335</sup> and have noted that, “allowing or even encouraging a person with cognitive or intellectual disability to ‘learn from mistakes’ may undermine efforts to protect that person from harmful outcomes.”<sup>336</sup> Also, some may find it cruel not to limit the agency of persons with cognitive impairments because if permitted to make their own decisions, they may suffer.<sup>337</sup>

The preceding discussion assumes it is possible to determine what is best for someone else.<sup>338</sup> But there are conceptual issues in defining and evaluating the quality of decisions, and determining whether a particular decision is good or bad.<sup>339</sup> In the healthcare context, questions about the quality of decisions and what is in someone’s best interests are typically never raised if there is agreement between the physician and patient on a course of action. When there is disagreement, however, the physician may find the patient to be incapacitated, which allows the patient’s will to be overridden without evaluating the quality of physician’s, surrogate’s, or patient’s decisions.<sup>340</sup>

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334. See Bruce Jennings, *Freedom Fading: On Dementia, Best Interests, and Public Safety*, 35 GA. L. REV. 593 (2001) (describing justifications for infringing the liberty of persons with dementia in terms of preventing harm to self and others). Bad decisions may also be decisions that others consider to be odd or weird, even if there is no risk of harm.

335. POWELL, *supra* note 4, at 161, 167, 204, 213, 235, 237; WORLD HEALTH ORG., *supra* note 27, at 47; see also Fetherstonehaugh et al., *supra* note 61, at 143 (describing potential conflicts between autonomy and wellbeing).

If wellbeing is not defined solely in medical terms, however, such conflicts may be eliminated. Alicia Hall, *supra* note 143, at 385 (“[P]atients are generally concerned with not just their physical but also their overall well-being when pursuing medical care . . .”). Indeed, scholars have noted that autonomy and safety are not always in tension. Fineman, *supra* note 323.

336. Kohn et al., *supra* note 13, at 1142. These experts assert that legislatures have responsibility for deciding what the balance between these values should be. *Id.*

337. Some facilities where persons with dementia live take the view that freedom is worth some risks of harm, however. Larissa MacFarquhar, *The Comforting Fictions of Dementia Care*, NEW YORKER (Oct. 1, 2018), <https://www.newyorker.com/magazine/2018/10/08/the-comforting-fictions-of-dementia-care>. But see Behrens, *supra* note 108.

338. HERRING, *supra* note 72, at 3.

339. When discussing how to evaluate supported decisionmaking, scholars have noted that studying the quality of decisions is not possible without agreement on what a good decision is. Hall, *supra* note 81, at 340; Kohn et al., *supra* note 13, at 1141–43.

340. Indeed, “[a] discrepancy between the person with dementia’s view and that of [others] may in some instances be as much to do with [others’] biases and assumptions . . . as with lack of awareness on the part of the person with dementia.” Woods & Pratt, *supra* note 62, at 426.



For persons with dementia, there may be danger that if they disagree with others, they will be deemed to lack decision-making capacity, even if under current capacity standards they could make their own decisions.<sup>341</sup> Indeed, a person with dementia may understand and prefer an option that appears to others to be suboptimal, but is actually an informed preference meant to further their interests, idiosyncratic as they are likely to be.

Given that capacitated individuals are routinely prevented from making their own healthcare decisions in current clinical practice,<sup>342</sup> arguments against supported decisionmaking on the basis of a possible negative impact on the person with dementia may be motivated by a desire to ensure that the person with dementia only has options that others, such as family members or healthcare providers, agree are good. This is because beneficence may be more highly valued than autonomy,<sup>343</sup> and there is an inclination to protect persons with dementia to the point of denying them the right to make their own decisions.

Respect for autonomy should trump beneficence, however, especially because the overall benefits of self-determination and relational decisionmaking may outweigh any negative effect of one “bad” decision. Indeed, research has demonstrated there are psychological benefits for persons with dementia and their families when they are involved in decisionmaking.<sup>344</sup> Additionally, there are also psychological benefits to supporters because when people collaborate in decisionmaking, they share the burdens of decisionmaking. Under the surrogate decision-making model, surrogates may feel distress about their decisions.<sup>345</sup> If a person eligible to be a surrogate is instead a supporter, there may be less stress and distress because their role and responsibility is not to decide for, but instead to provide decision-making assistance to, the person with dementia. Moreover, supporters will have agreed in advance of a decision to provide support in contrast to many surrogates who find themselves in the position of needing to decide for another with no notice, and this may also alleviate stress.

Furthermore, everyone faces the possibility of suffering from their decisions, regardless of their disability status, which raises questions about why only persons with decisional impairments have their liberty restricted. Indeed, scholars have pointed out that competent persons sometimes may be

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341. *Id.* at 428 (“Problems arise where the person with dementia does not share others’ views of their competencies, or does not accede compliantly to their views.”). When risks are assessed differently, others may override the autonomy of the person with dementia. *Id.* at 424.

342. Miller et al., *supra* note 8, at 1153.

343. Eltis, *supra* note 314, at 433–35; Woods & Pratt, *supra* note 62, at 424.

344. Miller et al., *supra* note 8, at 1152–53 (“[F]amily carers have better quality of life, less depression, less negative strain . . . For persons with dementia, being a part of the decision-making process may hold a grander meaning of validating their very existence or personhood, regardless of the outcome or who makes the final decision.”).

345. INST. OF MED., *supra* note 276, at 129, 137–39 (reviewing research).

worse off when they exercise their autonomy and make decisions seeking to effect their values.<sup>346</sup> This is because of background structural conditions or interpersonal relationships that restrict their set of possible choices,<sup>347</sup> incomplete information, and cognitive biases.<sup>348</sup> But people without cognitive impairments are typically not prevented from deciding for themselves, based on the theory that they are best positioned to know what is good for them. Despite the reality that people often do not make good decisions, they are allowed to do so. If persons with disabilities are to be treated equally, then their autonomy and self-determination must be respected<sup>349</sup> even if “bad” decisions result. Supported decisionmaking, where assistance is provided in making decisions, may temper concerns about bad decisions and cruel outcomes, however.

In conclusion, fears that supported decisionmaking will lead to bad decisions are not sufficient justification for denying persons with dementia agency. The current practice of marginalizing or excluding persons with dementia from healthcare decisionmaking, and relying on surrogates, is a *guaranteed* dignitary harm, which leads to a documented decrease in wellbeing.<sup>350</sup> Not preventing persons with dementia from making or participating in healthcare decisions could *possibly* result in harm (e.g., physical) and decreased wellbeing, but this is not guaranteed. On balance, if ensuring wellbeing of persons with dementia is the goal, then they should not be prevented from making their own decisions.<sup>351</sup>

346. Hawkins, *supra* note 4, at 514.

347. NEDELSKY, *supra* note 133, at 169; Donnelly, *supra* note 249, at 279; Harding, *supra* note 316, at 382; Sherwin, *supra* note 24, at 13–14.

348. KAHNEMAN, *supra* note 128; SCHNEIDER, *supra* note 61, at 144–45; THALER & SUNSTEIN, *supra* note 128, at 23–37.

349. See Bickenbach, *supra* note 324, at 123, 129 (discussing importance of equality of autonomy and arguing that to safeguard life and wellbeing of persons with disabilities, some individual’s autonomy may need to be sacrificed); see also Samuel R. Bagenstos, *From Integrationism to Equal Protection: tenBroek and the Next 25 Years of Disability Rights*, 13 U. ST. THOMAS L.J. 13 (2016) (arguing for the principle of equality to be applied to persons with disabilities); Sean M. Scott, *Contractual Incapacity and the Americans with Disabilities Act*, 124 DICKINSON L. REV. (forthcoming 2020) (arguing against mental incapacity doctrines in contract law because they discriminate against persons with disabilities who should be treated equally under the law).

350. See SABAT, *supra* note 132, at 181 (describing the positive benefits of promoting agency in persons with dementia and negative effects on quality of life when persons with dementia do not have a sense of agency); *supra* Section I.C; see also Mellers et al., *supra* note 152, at 68–69 (describing how when older persons remain in control, they have enhanced wellbeing).

351. Bruce Jennings, *Rethinking Dementia Care in Ethics and the Law*, 23 QUINNIPIAC PROB. L.J. 398, 410 (2010) (“[T]he principle that curtailing agency in dementia for the sake of safety, comfort, or expediency is not the path of morally responsible care giving or prudent public policy. Agency and selfhood of any kind eventually fade all too rapidly in the face of dementia. Let us not hasten their demise prematurely.”).

Supporters therefore should not be permitted to override the healthcare decision of the person with dementia, which is permissible under supported decision-making law in some other jurisdictions. Kohn et al., *supra* note 13, at 1121. Importantly, the effect on third parties of a person with dementia’s decision is still important to consider. Some decisions a person with dementia can

### *E. Dementia, Precedent Autonomy, and Personal Identity*

The onset of dementia raises significant questions about precedent autonomy and personal identity. In contrast to some other cognitive disabilities, such as Down Syndrome or autism, in which the person with the disability may never have been considered autonomous because they were born with cognitive impairments and for which there is no disruption in personal identity, many persons with dementia previously were viewed as capable and autonomous individuals.<sup>352</sup> And, unlike other disabilities that affect cognition where capacity will remain relatively constant (e.g., developmental disability) or may fluctuate with some predictability (e.g., mental illness), dementia is degenerative and capacity can be expected to decline over time. Both of these attributes of dementia lead to questions about the role of changed preferences, who the appropriate decisionmaker is, and what standard of decisionmaking should be used.

#### *1. Precedent Autonomy and Changed Preferences*

An individual's preferences and interests may change after they acquire dementia,<sup>353</sup> which raises philosophical, ethical, and legal questions.<sup>354</sup> The existing scholarly literature about these questions tends to focus on how decisions should be made on behalf of persons with dementia in light of changed preferences, and overlooks the possibility that a person with dementia could make their own decisions at the time a decision must be made.<sup>355</sup>

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make, such as expressing a preference to continue to drive, may justifiably be overridden due to concerns about harm to others. POWELL, *supra* note 4, at 242–43. While others may have an interest in the healthcare decisions of a person with dementia, the effects of most such decisions are internalized to the person with dementia and thus should be respected. *But see* Robert A. Burt, *The End of Autonomy*, 35 HASTINGS CTR. SPECIAL REP., Nov.–Dec. 2005, at S9, S12 (describing other's interests in a patient's decisionmaking). In brief, there are costs to respecting autonomy, such as a decline in medical wellbeing or negative externalities. *See supra* note 333. Those costs do not outweigh the benefits, however.

352. *See* Diller, *supra* note 11, at 525. If a person with dementia also has a developmental or intellectual disability, however, they may never have been considered autonomous.

353. Jaworska, *supra* note 4, at 108. There may be no discernable conflict between past and present preferences, however. *See, e.g.,* POWELL, *supra* note 4, at 14–16 (describing example of consistent healthcare preferences, despite presence of dementia).

354. WORLD HEALTH ORG., *supra* note 27, at 47 (noting that one ethical issue relating to dementia is “balancing a person's previous views and values with current ones”).

355. Recent proposals for changing decision-making practices for persons with dementia typically do not challenge the use of surrogates. Instead, the proposals change surrogate decisionmaking to incorporate elements of both substituted judgment and best interests standards to allow for preferences to change over time without ignoring precedent autonomy, and also to include the person with dementia in the decision-making process to some extent. Wilkins, *supra* note 102, at 1017–18, 1020; *see also* Marshall B. Kapp, *Medical Decision-Making for Incapacitated Elders: A “Therapeutic Interests” Standard*, 33 INT'L J. LAW & PSYCHIATRY 369, 369 (2010) (arguing for reconceptualizing best interests as broader than medical best interests and setting a minimum standard of what will promote a therapeutic end).

Some legal philosophers, such as Professor Ronald Dworkin, argue that respect for autonomy requires respect for the interests and decisions of the person when competent because only those were autonomous.<sup>356</sup> Professor Dworkin argues that wishes prior to the onset of dementia are dispositive to decisionmaking because a person's interests in how their experience with dementia fits into the narrative of their life as a fully competent and autonomous person is a critical interest (i.e., judgments about what makes a life good), which trumps mere experiential interests (e.g., any pleasure the person with dementia may experience).<sup>357</sup>

Those who agree with Professor Dworkin argue that a person with impaired decision-making abilities as a result of dementia

can make (mere) *choices*, but because the individual does not have the capacity to engage in the underlying process of deliberation that gives rise to genuine decisions, those choices are disconnected from his or her autonomous self. Giving the fullest possible effect to such an individual's autonomy in these circumstances requires giving effect to the decisions that the individual *would have made* if capable of making decisions . . . .<sup>358</sup>

Not all persons with dementia lack the capacity to deliberate, however, especially those in the early stages of dementia. Indeed, even scholars who in a Dworkinian vein argue for use of advance directives, which reflect earlier decisions, to hasten death in the event of dementia admit that a dementia diagnosis does not necessarily mean a person lacks decisional capacity.<sup>359</sup> Further, as discussed previously, there are significant questions about the extent to which persons without cognitive impairments make autonomous decisions.<sup>360</sup>

Other legal scholars, such as Professor Rebecca Dresser, argue that directives written prior to the onset of dementia should not be followed when they conflict with the person's current interests.<sup>361</sup> Professor Dresser explains that trying to guess one's future preferences and memorializing this in

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356. DWORKIN, *supra* note 1, at 218–29; *see also* Jesse Wall, *Being and Being Lost: Personal Identity and Dementia*, in THE LAW AND ETHICS OF DEMENTIA, *supra* note 11, at 327, 335 (describing Professor Dworkin's view of critical and experiential interests).

357. DWORKIN, *supra* note 1, at 199–208; *see also* Hawkins, *supra* note 4, at 510–11 (discussing Professor Dworkin's views).

358. Hall, *supra* note 81, at 339. Other scholars also note that autonomy requires certain cognitive abilities. Schindler & Waksman, *supra* note 58, at 352. Still other scholars argue that autonomy is the capacity to value rather than capacity to deliberate or “be fully in charge of one's life.” Jaworska, *supra* note 4, at 126.

359. Menzel & Steinbock, *supra* note 5, at 492 (describing a man with dementia who could not write, but could, with assistance, convey his thoughts).

360. *See supra* Section II.A.

361. Dresser, *Life, Death, and Incompetent Patients*, *supra* note 3, at 404–05; *see also* Menzel & Chandler-Cramer, *supra* note 39, at 28 (discussing when prior wishes should be followed in terms of a sliding scale).

an advance directive is problematic because one cannot know what one will want in the future.<sup>362</sup>

And, in fact, preferences, interests, and value judgments often do change when one develops a disability.<sup>363</sup> This is in part because persons without disabilities, including clinicians, do not accurately estimate the quality of life of persons of disabilities,<sup>364</sup> rating it lower than persons with disabilities report<sup>365</sup> and lower than they themselves report after they later acquire a disability.<sup>366</sup> Additionally, after becoming cognitively impaired, “what was once of extreme importance . . . no longer matters, while things that were previously of little moment assume much greater significance.”<sup>367</sup>

If preferences change after capacity is lost, a person with dementia may be unable to change their mind and act on their present interests because someone else has become the legal decisionmaker, or because their written instructions, which they may not remember or that express values they no longer care about, are considered legally binding.<sup>368</sup> That is, their former self binds their present self.<sup>369</sup> Professor Dresser thus prefers the best interests decision-making standard for persons with dementia.<sup>370</sup>

If persons with dementia used supported decisionmaking, it is unknown whether their decisions would match their former or current preferences and

362. Advance directives cannot anticipate all future scenarios one might face and one's preferences in each. POWELL, *supra* note 4, at 214; Dresser, *Precommitment*, *supra* note 3, at 1829–37; Wilkins, *supra* note 102, at 1017.

363. Sinoff & Blaja-Lisnic, *supra* note 61, at 101.

364. See Kohn et al., *supra* note 13, at 1141 n.122 (discussing problems with affective forecasting, especially when imagining life with a disability); Wright, *supra* note 251 **Error! Bookmark not defined.**, at 27–28 (discussing quality of life of persons with dementia).

365. David Orentlicher, *Deconstructing Disability: Rationing of Health Care and Unfair Discrimination against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49, 69 (1996).

366. Norman F. Boyd et al., *Whose Utilities for Decision Analysis?* 10 MED. DECISION MAKING 58, 66 (1990).

367. Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 236 (1989).

368. Dresser, *Life, Death, and Incompetent Patients*, *supra* note 3, at 379–81.

369. Dresser, *Precommitment*, *supra* note 3, at 1825. Expressing different wishes after one acquires a cognitive impairment may constitute a revocation of an advance directive, in which case precommitment would not be a problem. The UHCDA expressly considers revocation of an advance directive. UHCDA, *supra* note 2, at § 3; see also Callahan, *supra* note 150, at 26 (“We would do well to be suspicious of such earlier declarations when the evidence before our eyes is that of a patient doing reasonably well and not obviously seeking death.”).

370. Dresser, *Life, Death, and Incompetent Patients*, *supra* note 3, at 374. Other scholars also argue for use of the best interests standard. Woods & Pratt, *supra* note 62, at 428. For a defense of Dresser's privileging of current interests over prior wishes in terms of autonomy rather than best interests, see Ells, *supra* note 133, at 613.

interests. But supported decisionmaking would ensure that a person with dementia could agentically decide to further what they view as their current best interest and would not be bound to former preferences.<sup>371</sup>

## 2. *Dementia, Numerical Identity, and Decisionmaking*

When a person acquires dementia, questions arise about whether they are the same person as before they had dementia.<sup>372</sup> Dementia, unlike many other disabilities, involves “[a] long process of personality changes—which may affect the validity of the patient’s prior wishes and advanced directives.”<sup>373</sup>

This issue is often referred to in terms of *numerical* personal identity.<sup>374</sup> If dementia causes identity to change, to the point that the individual may no longer be the same person,<sup>375</sup> then how should advance directives be considered? This question is deeper than those dealing with what to do in the case of changed preferences after the loss of decisional capacity. As a general matter, people do not decide what happens to other’s bodies, unless they have special moral or legal authority. Under this principle, it is not clear why a stranger who happened to inhabit the same body as the person with dementia

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371. See POWELL, *supra* note 4, at 14–16 (describing case of woman with severe dementia whose healthcare preferences remained strong and consistent); see also John K. Davis, *Precedent Autonomy and Subsequent Consent*, 7 ETHICAL THEORY & MORAL PRAC. 267 (2004) (discussing resolution preferences that dictate whether to respect precedent autonomy or current preferences); Jaworska, *supra* note 4, at 126 (describing how receiving assistance in living “according to [one’s] convictions and values” is not inconsistent with autonomy).

372. Some persons with dementia believe themselves to be a different person after the onset of their illness. For example, one person with dementia told researchers, “I hope we’re not going to discuss the past much, because I’m no longer the person that I was then.” Yale & Snyder, *supra* note 291, at 234. Family members may think the person with dementia is fundamentally the same. CASTLEMAN ET AL., *supra* note 31, at 11.

373. Golan, *supra* note 71, at 415–16. Other brain-based disabilities may affect personality and identity in similar ways, however. And arguably identity changes throughout the life course regardless of whether one becomes disabled. Woods & Pratt, *supra* note 62, at 428.

374. See Allen Buchanan, *Advance Directives and the Personal Identity Problem*, 17 PHIL. & PUB. AFF. 277, 280 (1988) (discussing identity in terms of “psychological continuity”); Elisabeth Furberg, *Advance Directives and Personal Identity: What is the Problem?*, 37 J. MED. & PHIL. 60, 61 (2012) (assessing the moral relevance of “psychological continuity” for following advance directives). This is also known as the “someone else” problem. David Degrazia, *Advance Directives, Dementia, and “The Someone Else Problem,”* 13 BIOETHICS 373, 373 (1999). For recent experimental scholarship on the issue of dementia and numerical identity, see Stephen R. Latham & Brian Earp, Presentation at 21st Annual Conference of the American Society of Bioethics and Humanities: Experimental Philosophy and Advance Directives in Dementia, (Oct. 24, 2019).

375. Wall, *supra* note 356, at 372 (describing identity over time as numerical identity). Some bioethicists argue, however, that there is numerical identity between the person pre- and post-dementia. NUFFIELD COUNCIL ON BIOETHICS, DEMENTIA: ETHICAL ISSUES xviii (2009).

should get to make decisions for what will happen to that body at a later date when occupied by a different person.<sup>376</sup>

Supported decisionmaking provides a solution to this conceptual and ethical problem. If the person before the onset of dementia is not the same as the person after dementia, then the current preferences and interests of the person with dementia should be the only considerations in decisionmaking, and supported decisionmaking would facilitate decisionmaking on these bases. If the person before the onset of dementia is the same as the person after dementia, then retaining decision-making authority permits the person to either make decisions consistent with their prior wishes, or to change their mind.<sup>377</sup> One does not have to know the answer to the question of whether there is numerical identity pre- and post-dementia because supported decisionmaking is appropriate regardless of the answer.

### 3. *Dementia, Personhood, and Decisionmaking*

There are also questions about whether someone with dementia retains any identity (or personhood) throughout the experience of illness. Philosophers have analyzed the qualitative component of personal identity in this context. If identity is viewed as consisting of cognitive abilities, then when cognitive abilities change or decline, identity so too changes and may even constitute a “loss of self.”<sup>378</sup> This leads to a debate about whether a person with dementia can act as a subject<sup>379</sup> or is acted upon as an object, perhaps owed “duties of benevolence and dignity,” but not a recognition of autonomy.<sup>380</sup>

Persons with dementia may feel a loss of personhood when interacting with others who assume they are incapable and attempt to assert their status as *persons* who can still make their own decisions. As one woman at an AD support group commented, “We will talk about it. I will listen, but you must talk with me about it so that I can make an informed decision—it’s my decision.”<sup>381</sup> Another woman with AD conveyed, “I still would like to be treated like a person, you know, because I’m still a person whether I do it wrong or

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376. See Wilkins, *supra* note 102, at 1018 (arguing that in these circumstances, following an advance directive or making a substituted judgment is like “asking an unrelated stranger to ultimately make the decision”). As some have argued, as psychological continuity decreases, the moral force of the advance directive weakens. Buchanan, *supra* note 374, at 301. Others find this entire argument unpersuasive and argue that the focus should not be on identity but on efficacy of proposed medical treatment. POWELL, *supra* note 4, at 257–58; Davis, *supra* note 4, at 747.

377. This would be considered a revocation of their advance directive.

378. Wall, *supra* note 356, at 329, 334, 336; see also CASTLEMAN ET AL., *supra* note 31. Or constitute a “mere self” with no personhood. Degrazia, *supra* note 374, at 389–90. But see MacFarquhar, *supra* note 337 (“Why should a person be defined by thoughts and memories? Aren’t emotions and bodies enough?”).

379. Wall, *supra* note 356, at 330.

380. *Id.* at 333.

381. Snyder, *supra* note 91, at 120.

right.”<sup>382</sup> And a support group participant newly diagnosed with AD asked, “Will I soon not be a person anymore?”<sup>383</sup>

If personal identity is instead viewed as a relationship between an individual and the external world,<sup>384</sup> or as anything other than cognitive abilities such as the “capacity to feel emotions,”<sup>385</sup> a person with dementia may retain personal identity and remain the subject of their lives.<sup>386</sup> Persons with dementia can use supported decision-making agreements that declare they have the right to make their own decisions as a means to assert their personhood.

On a concluding note, some scholars assert that both numerical identity and personhood remain largely intact over the course of dementia, and that any changes are due to how others construct the significance of dementia.<sup>387</sup> If this is the case, then interventions, such as supported decisionmaking, that alter how others interact with a person with dementia may obviate concern about changes to personal identity.

#### *F. More Research on Supported Decisionmaking Is Needed*

Much is unknown about the practice and effects of supported decisionmaking. As the authors of an article reviewing studies of supported decisionmaking conclude, “[T]here is almost no evidence as to how decisions are actually made in supported decision-making relationships; the effect of such relationships on persons in need of decision-making assistance; or the quality of the decisions that result.”<sup>388</sup> Because of this absence of information about supported decisionmaking, it is impossible to know conclusively whether this model accomplishes the goal of promoting self-determination for persons with disabilities.<sup>389</sup> But given the importance of respect

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382. *Id.* at 116.

383. Yale & Snyder, *supra* note 291, at 235.

384. Wall, *supra* note 356, at 329; *see also* HERRING, *supra* note 72, at 12, 59 (describing identity and relationships); Harding, *supra* note 316, at 381 (describing relationality compared to autonomy).

385. KITWOOD, *supra* note 43, at 7; POWELL, *supra* note 4, at 221.

386. Indeed, recent scholarship has argued that communication and relationships are what constitute personhood and “enable people with dementia to be actively engaged for as long as possible as primary decision makers about the course of their lives.” Wilkins, *supra* note 84, at 638; *see also* Jennings, *supra* note 137 (discussing relationships, personhood, and remaining agency and identity of persons with dementia); Jennings, *supra* note 62 (arguing that relationships can preserve the personhood of persons with dementia); Jennings, *supra* note 334, at 614–15; Wall, *supra* note 356, at 333.

387. KITWOOD, *supra* note 43, at 44–58, 64–77, 78–82 (discussing how others undermine the personhood of persons with dementia and how personhood can be maintained); Sabat, *supra* note 85, at 90; Series, *supra* note 86, at 106 (“[I]t is often not so much the impairment itself, but the response of society around the person that creates much of the misery and suffering of dementia.”); *see also* SABAT, *supra* note 132, at 137–49 (describing selfhood and dementia); STEVEN R. SABAT, *THE EXPERIENCE OF ALZHEIMER’S DISEASE: LIFE THROUGH A TANGLED VEIL* (2001).

388. Kohn et al., *supra* note 13, at 1114.

389. *Id.*



for autonomy and the potential for increased wellbeing when law aligns with people's preferences, supported decisionmaking is worth adopting into law.

Moreover, while the empirical research on supported decisionmaking is very limited,<sup>390</sup> there is more information from another type of relational decision-making model, shared decisionmaking, which can be useful in drawing inferences about supported decisionmaking.<sup>391</sup> Shared decisionmaking occurs when a patient and physician decide together on a particular healthcare decision. The patient describes their values and preferences, and the physician offers recommendations based on their medical expertise in light of their patient's values.<sup>392</sup> This model is meant to promote patient autonomy while providing support in the decision-making process,<sup>393</sup> similar to the goal of supported decisionmaking.

The available research on shared decisionmaking for a variety of patient populations demonstrates that many patients desire this form of decisionmaking, but physicians do not engage in it as a matter of routine practice.<sup>394</sup> Other research has revealed that the degree to which patients find shared decisionmaking valuable depends on the type of decision and the patient's age,<sup>395</sup> and that a significant number of people prefer not to actively make healthcare decisions, instead deferring to their physician.<sup>396</sup> The research is unclear whether shared decisionmaking leads to better outcomes,<sup>397</sup> but suggests that this model does not lead to worse outcomes.<sup>398</sup>

Despite the lack of knowledge about the practice of supported decisionmaking, there are reasons to adopt it into legislation. This model has symbolic appeal because it provides legal support for the capabilities and self-determination of persons with disabilities, including dementia, and there

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390. For a recent review of the literature on supported decision making, see Karrie A. Shogren et al., *Supported Decision Making: A Synthesis of the Literature Across Intellectual Disability, Mental Health, and Aging*, 52 EDUC. & TRAINING IN AUTISM & DEVELOPMENTAL DISABILITIES 144 (2017).

391. Kohn et al., *supra* note 13, at 1146–48.

392. INST. OF MED., *supra* note 276, at 166–67; Dan W. Brock, *The Ideal of Shared Decision Making Between Physicians and Patients*, 1 KENNEDY INST. ETHICS J. 28, 28 (1991); Kohn et al., *supra* note 13, at 1147; Sinoff & Blaja-Lisnic, *supra* note 61, at 97–98.

393. Kohn et al., *supra* note 13, at 1147–48.

394. INST. OF MED., *supra* note 276, at 351. Some have suggested that financial incentives might motivate physicians to engage in greater shared decisionmaking. Kohn et al., *supra* note 13, at 1153. *But see* Wright, *supra* note 299.

395. Kohn et al., *supra* note 13, at 1149–50.

396. *Id.* at 1150; Sinoff & Blaja-Lisnic, *supra* note 61, at 98.

397. Kohn et al., *supra* note 13, at 1151–52.

398. *Id.* at 1152. There is a lack of research on shared decisionmaking with patients who have cognitive disabilities. *Id.* at 1148–49. But if the findings from the wider shared decision-making literature apply to supported decisionmaking for persons with dementia, then one would expect that 1) some patients with dementia will opt out of decisionmaking entirely based on individual preferences and 2) that engaging in supported healthcare decisionmaking would not cause harm.

is no evidence of concrete harm from its use.<sup>399</sup> Conducting more research on supported decisionmaking remains important, however.<sup>400</sup>

## V. CONCLUSION

As some scholars have observed, “Too often, it appears, we take the limitations imposed on the liberties and dignity of those with dementia for granted, as a presumed natural consequence of their degenerating health and our well-intentioned but paternalistic desire to ensure their medical well-being.”<sup>401</sup> These presumptions are embedded in healthcare decision-making laws, policies, and practices, all of which permit others to decide for a person with a decisional impairment such as dementia.

The rise in the number of persons living with dementia means that surrogate healthcare decision-making laws will impact more people, and it is thus imperative to examine whether these laws respect autonomy and promote wellbeing. Some argue that advance directives and surrogate decisions based on substituted judgments adequately respect (prior) autonomy. This Article instead argues that institutionalizing supported decisionmaking, a model found in disability and guardianship law, would best respect the exercise of (current) autonomy of many persons with dementia and would also enhance their wellbeing.

The underlying rationale for surrogate decisionmaking for persons with dementia is that only autonomous persons are entitled to make their own healthcare decisions. Persons who are not autonomous are entitled only to beneficence or respect for precedent autonomy. This rationale relies on the assumption that persons with dementia are not, by virtue of their disability, autonomous. This Article argues, however, that many persons with dementia are in fact capable of autonomy.

Autonomy as understood by many philosophers, clinicians, and legal actors is a fiction.<sup>402</sup> Behavioral economics literature demonstrates, for example, that people often do not decide rationally because their decisionmaking is distorted by various cognitive biases. Sociological and philosophical

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399. Terry Carney, *Participation and Services Access Rights for People with Intellectual Disability: A Role for Law?*, 38 J. INTELL. & DEVELOPMENTAL DISABILITY 59, 62 (2013).

400. If used for persons with dementia, it would be particularly important to know whether supported decisionmaking resulted in perceptions of increased agency and wellbeing for persons with dementia compared to surrogate decisionmaking. Additionally, it will be important to identify barriers to implementation, and so it is also important to know what healthcare providers and family members think of supported decisionmaking and whether they can identify ways to improve the model. See KAPP, *supra* note 73, at vii–viii (describing how the effects of laws are unknown, but should be known).

401. Eltis, *supra* note 314, at 433.

402. See BEAUCHAMP & CHILDRESS, *supra* note 23, at 104 (defining autonomous decisions as intentional and voluntary, and made with understanding).

scholarship also demonstrates that people cannot be truly autonomous because the set of choices from which decisions are made is limited by structural conditions or through interactions with others.<sup>403</sup> Other scholarship has focused on the special setting and nature of medical decisionmaking, highlighting that people are sick, afraid, and do not understand the complexity of proposed medical interventions, which suggests that autonomous decisionmaking is especially difficult in this context.

Given this, some have argued that privileging autonomy in healthcare decisionmaking has been a failure and that other principles, such as hard paternalism or considering effects on third parties, should be emphasized instead. I disagree. Respect for bodily integrity in the healthcare setting is of utmost importance, and respect for autonomy may be the best way to respect a patient's bodily integrity. Further, deemphasizing autonomy may disproportionately harm persons with disabilities who have long struggled to be respected as persons and recognized as capable of self-determination.<sup>404</sup> Finally, feeling autonomous can lead to increased wellbeing.<sup>405</sup>

Instead, I argue for reconceptualizing autonomy to accord with decision-making reality.<sup>406</sup> Decisionmaking for persons without cognitive impairments who are presumed to be competent is, at best, *autonomish*. Or, stated differently, decisionmaking is an exercise of agency rather than autonomy defined by its ideal type.<sup>407</sup> When autonomy is understood as agency, it becomes much more difficult to justify the marginalization or exclusion of persons with MCI or mild dementia from healthcare decisionmaking. This is because many such persons, despite their cognitive impairments, retain the ability to articulate their values,<sup>408</sup> assert their preferences, and choose between healthcare options, just as persons without dementia can. That is, persons with MCI or mild dementia remain able to exercise their agency, if not prevented from doing so by well-intentioned physicians or family members. Applying the principle of *equal* respect for persons demands respecting the agency of persons with dementia, just as the agency of persons without dementia is respected.<sup>409</sup>

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403. Crossley, *supra* note 151, at 906–08.

404. *Id.* at 909. Additionally, many persons with disabilities do not trust that “all persons and institutions involved in those decisions will respect the experiences, values, and welfare of people with disabilities,” which is further reason to emphasize autonomy. *Id.* at 897.

405. SABAT, *supra* note 132, at 181; Mellers et al., *supra* note 152, at 68–69.

406. See Ells, *supra* note 133, at 614 (“[A] new . . . conception of autonomy needs to be worked out that includes what has been learned from the experience of self . . . under conditions of disability.”).

407. See *supra* Section II.A.

408. See Jaworska, *supra* note 4, at 109 (arguing that persons with dementia who have the capacity to value are able to be autonomous).

409. Bickenbach, *supra* note 324, at 123 (“The fact of the social devaluation of the life of persons with disabilities, as a matter of both attitude and practice, demands that the governing moral principle ought to be equality, and in particular equality of autonomy.”).

Relatedly, I have argued in past work for conceptualizing autonomy in late- and end-of-life decision-making law and policy as relational.<sup>410</sup> Studies documenting decision-making preferences and practices in this context reveal that the exercise of autonomy is relational in two dimensions: deciding in consultation or collaboration with others and deciding, in part, on the basis of other's interests.<sup>411</sup> I continue this work in the present Article by arguing that persons with dementia should take advantage of supported decisionmaking, which is inherently relational, as principals seek, and supporters provide, assistance with decisionmaking. Supported decisionmaking also allows for principals, should they prefer, to act altruistically and decide on the basis of other's interests. In brief, supported decisionmaking aligns with how persons without cognitive impairments prefer to make important healthcare decisions, formalizing what is often done informally, and is consistent with the practice of relational autonomy.

Combining these insights, "autonomy" in healthcare decisionmaking is better described as agency, which is relational in practice. Persons with mild to moderate dementia are capable of exercising *relational agency* when making healthcare decisions, and this capability should be respected in law and clinical practice.

Relying on supported rather than surrogate decision-making law accords with relational agency and is responsive to the preferences and interests of persons with dementia in remaining free to make their own decisions. Supported decisionmaking thus may increase the wellbeing of this population. For these reasons, this model of decisionmaking should be adopted into law in all states and routinely used for persons with dementia.

Expanding decision-making options is not the only change that should occur, however. Future scholarship should focus on other changes necessary to fully expand autonomy and further increase wellbeing for persons with dementia as well as others making medical decisions in late life.<sup>412</sup> Solving problems of access to quality long-term care is one such policy priority because not having such access affects the healthcare decisions that patients and families make.<sup>413</sup> Indeed, this Article should not be read as absolving the state of its responsibilities to care for vulnerable populations,<sup>414</sup> "[i]ndividualizing a [s]ocial [p]roblem,"<sup>415</sup> or privileging decision-making rights and legal capacity over social and economic rights.<sup>416</sup> As I have noted elsewhere, "Considering the generosity of the social safety net matters . . . [and] [w]hile

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410. Wright, *supra* note 20, at 1066–68.

411. *Id.* at 1093.

412. Blank, *supra* note 50.

413. POWELL, *supra* note 4, at 161, 167; Wright, *supra* note 20, at 1099 n.203.

414. Fineman, *supra* note 323, at 98 (arguing that resources are needed to enhance autonomy).

415. Dresser, *Precommitment*, *supra* note 3, at 1844–46.

416. Kanter, *supra* note 74.

the focus of this paper has been mostly on the micro-level of decisionmaking . . . it is also important to consider the macro-level conditions that influence autonomy.”<sup>417</sup>

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417. Wright, *supra* note 20, at 1099 n.203.